

DEVELOPMENTAL DISABILITIES
Advocacy Programs and State Plans
- A FIVE-STATE SURVEY -

This volume contains two reports,
Advocacy Programs for the Developmentally Disabled
and
Developmental Disability Plans

Prepared for the
EXECUTIVE OFFICE OF THE GOVERNOR
STATE OF MINNESOTA

By the
Institute for Interdisciplinary Studies
123 East Grant Street
Minneapolis, Minnesota 55403

December 20, 1971

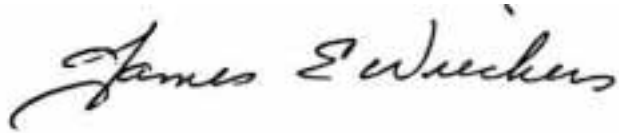
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Approved for
INSTITUTE FOR INTERDISCIPLINARY STUDIES

A handwritten signature in black ink that reads "James E. Wiechers". The signature is written in a cursive style with a large, stylized initial "J".

James E. Wiechers, Ph.D.
Director
Educational and Occupational Research Division

ADVOCACY PROGRAMS
FOR THE DEVELOPMENTALLY
DISABLED

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PREFACE

The intent of the Developmental Disabilities Services and Facilities Construction Act (P.L. 91-517) is to supplement and augment existing state/federal programs in extending care for persons who are substantially handicapped due to mental retardation, cerebral palsy, epilepsy, or other neurological conditions.

To assist Governor Wendell Anderson in implementing the Minnesota State Plan under P.L. 91-517, the Institute for Interdisciplinary Studies (IIS) has conducted investigations of developmental disability programs in existence in other states.

This report, one of three prepared by IIS for the Office of the Governor, concerns advocacy programs related to developmental disabilities in the states of Kansas, Nebraska, Ohio, Pennsylvania and Wisconsin.

ADVOCACY PROGRAMS FOR THE DEVELOPMENTALLY DISABLED

I. Concepts of Advocacy

An advocate, as defined in Webster's New Collegiate Dictionary, is either "one that pleads the cause of another," or "one that defends or maintains a cause or proposal." The first type of advocate, "one that pleads the cause of another," could be termed an individual advocate. On a one-to-one basis with a client, the individual advocate represents the client's interests as if they were his own. Lawyers have represented the interests of individuals for centuries; however, in recent years there has been a trend for professional and non-professional people in many other fields to help others secure their rights and fulfill their needs in the areas of health, social services, education, and law.

The second type of advocate, "one that maintains or defends a cause or proposal," could be called a group advocate. A group advocate acts in the interests of either an entire population or a certain sector of that population. Most voluntary agencies, special interest groups, lobbyists, and even public relations personnel, are group advocates.

Individual advocates may be professionals, paid non-professional workers or community volunteers. For the developmentally disabled, professional social workers may act as individual advocates from within either a public, private, or voluntary agency. Agencies also might elect to hire non-professional workers and train them in a variety of advocacy functions. Community volunteers, ranging from members of youth groups to senior citizens, are frequently utilized by private organizations and community groups, but seldom by public agencies.

There are many possible tasks involved in individual advocacy for the developmentally disabled. Although it is unlikely that any one advocate would function in all areas, the following are examples of potential tasks of the individual advocate:

1. Provide information to potential consumers of a service concerning the quality of that service and the sponsoring organization.
2. Provide information to a potential consumer concerning the type of services available.
3. Encourage persons to use existing community resources.
4. Inform persons about their legal rights in obtaining services from an organization.
5. Refer persons to community resources.
6. Act as an advocate for a specific person to insure that he is accepted for services, and that he will obtain a reasonable benefit.
7. Follow up persons referred to a resource to determine if the recipient is satisfied with the services and the result.
8. Assist a person in recognizing when and what services are needed.
9. Assist service agencies in coordinating a program for the individual when multiple services are necessary.
10. Aid the individual in coping with problems of everyday living. In working with a disabled person this may include such things as providing transportation, assisting with shopping, and working out special home-making problems or teaching basic skills.
11. Protect the civil and human rights of the individual by recognizing violations of those rights and informing appropriate legal and other agencies.
12. Provide encouragement, friendship, and advice to the disabled person and his family.

Any of these tasks might be a function of any of *the* three types of workers mentioned above; however, there is a tendency for professional workers to handle legal, referral, and counseling functions and for volunteer workers to help the disabled as friends in problems of daily living.

A group advocate might be a single person but is more likely to be an organization. While individual advocacy seeks to provide existing services and immediate help to a client, group advocacy is frequently directed toward changes in laws, public attitudes, services available, or the structure and interaction of agencies. The scope of group advocacy is broader than individual advocacy and generally requires resources beyond the abilities of a single person. The following tasks are examples of areas that might be appropriate for group advocacy:

1. Attempt to modify or change legal but abusive and discriminatory policies, practices, and procedures (hiring restrictions, inferior workmanship, over pricing, poor quality of services, etc.).
2. Provide consultation or technical assistance to an organization that will improve the performance of the organization.
3. Raise funds for an organization or special interest group.
4. Assist similar or related organizations to plan cooperative programs, coordinate services, etc.
5. Attempt to enact legislation that would create new resources, improve funding, provide better regulation, improve services, etc.

Special interest groups of any kind – private agencies for the disabled, voluntary and parent groups, and advisory committees

may serve advocacy functions. The composition of the group, interests and abilities of the individual members, and needs of the population represented will determine particular program areas. Over the last 15 years there has been a gradual shift in the types of activities sponsored by voluntary associations for the developmentally disabled. Direct services to the disabled have received less emphasis, and advocacy, particularly in the areas of public education and legislation, has been emphasized. Direct services to the disabled are now largely provided by public agencies with voluntary agencies accepting responsibility for providing information to the public, technical assistance to national, state and local governments in planning programs and lobbying for liberalized legislation pertaining to the disabled.

The role of the much discussed ombudsman should be defined in relation to the concept of advocacy. An ombudsman, who is generally a public employee, is expected to act on behalf of citizens' interests with complete impartiality. An ombudsman receives complaints, investigates them, and can recommend action. However, his role is to see that everyone is "following the rules." Typically, he does not pursue an issue beyond the point of making a recommendation.

The advocate, on the other hand, is supposed to represent the client from the client's perspective. He should not be impartial. Ideally, advocates should not work directly for, and possibly not even be funded through, any governmental or private agency that they are likely to deal with in representing their clients because of obvious conflicts of interest.

II. Information on Programs in Other States

Telephone contact was established with state and private agencies involved with developmental disabilities in Wisconsin, Kansas, Nebraska, Ohio and Pennsylvania. The agencies were requested to supply information concerning their efforts in establishing advocacy programs, particularly in relation to disability programs. Information items requested include:

Purpose of the advocacy program How the program is structured Length of time in operation Agencies involved Cost of program Public reaction Problems encountered Measures of effectiveness Future plans (See Appendix A for complete list of interview questions.)

In addition, the Institute for Interdisciplinary Studies has performed a literature review and summarized findings in the area of advocacy for general background information. It is believed that the information obtained from the state surveys and literature review will provide the State Planning and Advisory Council with a variety of possible approaches to development of an advocacy program and serve as a general basis for initial estimation of cost and benefit of such programs.

Representatives of public and voluntary agencies related to the developmental disabilities in Pennsylvania, Ohio, Kansas,

Wisconsin, and Nebraska were interviewed by telephone to gather information on current advocacy programs in those states (see Appendix B for list of interviews). Due to time constraints, the number of interviews was limited. Much of the written information promised by other states has not yet arrived. As a result, the program descriptions in this section may be incomplete. As far as can be determined, the three individual advocacy programs related to developmental disabilities are the only ones in operation in the states surveyed, and there are no ombudsmen in any of the states who deal specifically with the disabled. It is possible, however, that ombudsmen with more general interests and responsibilities were not mentioned in the interviews.

All of the states surveyed have state branches of the Association for Retarded Children, the Epilepsy League, United Cerebral Palsy, and other voluntary organizations. These organizations all engage in group advocacy either formally or informally. It was felt that because group advocacy for the disabled is already an established practice in voluntary organizations and is, therefore, more familiar than individual advocacy, information on programs of individual advocacy would be more useful to the State of Minnesota at this time. Therefore, in view of true constraints, little information was collected on group advocacy.

Individual advocacy programs for the developmentally disabled in Nebraska, Ohio, and Wisconsin are included in this discussion. Pennsylvania and Kansas have no formal advocacy programs for the developmentally disabled. Detailed information on advocacy programs in Minnesota can be found in the accompanying report, "Survey of Programs for the Developmentally Disabled in Minnesota."

Nebraska

Nebraska has an ongoing advocacy program for the mentally retarded which is funded and coordinated through the Office of Mental Retardation and carried on by a parent group called the Capitol Association for Retarded Children.

Projects in Lincoln and Omaha, the state's two largest population centers, are operational. In Lincoln, the program served approximately 90 retarded individuals in the past year. The Omaha project has only recently begun and is currently serving four retarded persons. Information on characteristics of the clients, projections of future numbers to be served, plans for expansion, and estimates of number of retarded persons who could benefit from the service were not available.

The Capitol Association employs two full-time staff members to supervise the advocates, who are unpaid volunteers. The paid staff members recruit, select and train volunteers; they match advocates to the retarded clients to be sure that they are personally compatible, and act as resource persons for the advocates.

Specific information on recruitment procedures was not available. Mass media are apparently utilized, but to what extent is unknown. Recruitment efforts are aimed at all age groups from 'teens through senior citizens and people from all walks of life.

Criteria used in screening volunteers are unclear, but apparently anyone who is sincerely interested in working with a retarded person is accepted for training. The training sessions familiarize volunteers with mental retardation generally, and involve one-to-one interaction with the retarded. From the interviews, it is not apparent how much advocates learn about types of services

available to the retarded, civil and human rights, and legislation concerning the retarded. It is our impression at this time that this information is not covered in depth in the training sessions but that as the advocate and retarded clients become better acquainted and the advocate wishes to expand his role, the information is made available by the paid staff members.

Data are not kept on characteristics of the volunteers, but people involved in the program say that the volunteer group has a diverse membership made up to a large extent of teenagers, housewives, and the elderly, but with many other groups represented.

There are no specific tasks required of the advocates, and all types of individual advocacy are represented, from friendship and the teaching of home making skills to working with public agencies in efforts to modify practices and policies considered adverse to the interests of the retarded.

The problem of defining the best interests of the retarded individual is handled by "letting the individual express his own needs as much as possible or giving the individual alternatives to choose from," according to one interviewer. Another source said that needs of a retarded person are thoroughly investigated by the advocacy office and that he is then matched with an appropriate advocate. The procedures used were not specified.

Program staff members felt that follow-up and evaluation are problem areas in the program. Advocates are asked to send in monthly progress reports but seldom do. The staff members maintain informal contact with the advocates and retarded clients

and feel that at this point expressions of enthusiasm from the participants are probably the best possible indicators of the positive impact of the program on the people involved. In addition, it is believed that the program has generated new interest in providing high quality services on the part of other agencies and organizations. One interviewee indicated that success might be measured by the lower incidence of retarded persons returning to state homes.

Ohio

The Ohio advocacy program is the only one of the three surveyed that is funded by the Developmental Disabilities Act. The total program budget is \$31,000 for fiscal year 1972 - \$23,000 in federal monies and \$7,700 in matching funds raised through the United Appeal. The project area is Franklin County, Ohio (Columbus). The Ohio Association for Retarded Children operates the project under contract with the Franklin County Council. The program is not yet fully operational; it was started on October 1, 1971 and at the time staff members were contacted, recruitment of volunteer advocates had been underway for only three weeks. It should be recognized that information included in this section is based more on the expectations of the staff members interviewed than on experience. Documents describing the program plans in detail have not yet been received from the Association for Retarded Children office.

There are three paid staff members assigned to *the* advocacy project: a project coordinator-supervisor, one part-time person who follows up on advocate-retarded client pairs, and a secretary. There are currently 15 volunteer advocates. More are expected, but estimates of the probable final size of the program are not available. The advocates are recruited through mass media. In the Columbus area, television has proved a more effective advertising medium than radio and newspapers. As in Nebraska, volunteers are screened before being accepted as advocates, but criteria used in screening are not formal. So far, no one who has applied as an advocate has been rejected.

Advocates, again, are mainly teenagers, housewives, and the elderly. The Association for Retarded Children noted that physically handicapped people in Columbus have expressed interest in working with the retarded. (One of the present advocates is a woman who has had both legs amputated.) The advocacy staff intends to encourage more physically disabled persons to act as advocates.

No particular tasks are required of the advocates. Some teach cooking and home making skills, some help in shopping, etc. The staff expects that as the program continues the advocates will become more aggressive in representing the retarded to service-providing agencies.* However, they consider the friendship role of the advocate top priority.

*Although this program is funded by the Developmental Disabilities Act, the clients are currently all mentally retarded. The Ohio Association for Retarded Children expects to expand the project to cover cerebral palsy and epilepsy; however, it was not clear in the interviews what, if any, changes in the program are considered necessary to serve non-retarded developmentally disabled.

The part-time staff worker follows up on the advocates and retarded clients every six weeks to two months. Her function is to see that the pairs are well matched, to provide advice and encouragement, and to note the types of activities they have been engaging in.

The "best interests" of the retarded are considered "normalization," according to project staff, although the advocates themselves are hesitant to use the term, considering it too impersonal. They express it as "being able to lead a normal life." It is not clear how and by whom decisions are made on what activities are necessary to accomplish this goal. Because the program has just begun, no information on impacts on individuals, public opinion, or agencies is available.

Wisconsin

Wisconsin conducted a pilot project on "Protective Services," basically an advocacy program, that ran from April to August, 1971. Unlike the Ohio and Nebraska advocates, the advocates in Wisconsin were professional staff members. The Protective Services Project is run by the Wisconsin Association for Retarded Children (WARC) and is funded by money from the state's health planning grant under Section 314D of the Public Health Service Act. There are two full-time professional staff members working on the project and 21 retarded clients. The clients were drawn from two Wisconsin counties, Dane and Iowa, which were chosen as representative of urban and rural counties.

Clients were referred to the program by the Association for Retarded Children, county welfare departments, public health departments, and private individuals. A major objective of the project was to study the feasibility of offering a statewide protective service through the Wisconsin Association for Retarded Children. The Association estimates that there are between 600 and 650 retarded individuals in the two counties in which the pilot was conducted and 125,000 retarded persons across the state who could benefit from an expanded program.

The following services were provided, with the understanding that additional services might later be incorporated into the program:

1. Counsel adult mentally retarded persons and their families (friendship impact).
2. Act as advocate for the adult mentally retarded and their families through "helping" systems.
3. Arrange referrals for the adult mentally retarded and their families to agencies and services with follow-up . procedures.
4. Provide information concerning guardianship to the adult mentally retarded and their families.
5. Seek out adult mentally retarded citizens who need services.
6. Establish a continuous follow-up system (a case is never considered closed).
7. Observe and react to the needs of each retarded individual to make sure appropriate services for each person are realized.

In the pilot project, services were centralized under the state office of the Wisconsin Association for Retarded Children. With increased caseloads services would be decentralized, using the Wisconsin Association for Retarded Children administrative districts to insure easy access to services and maximum possible contacts between staff and client. Workers were successful in obtaining and coordinating services for the retarded clients and identified many gaps in service delivery. The project is considered a success and the sponsors would like to continue and expand it (see Appendix C for final project report).

III. Summary and Conclusions

The term advocacy is used to express several different concepts and to describe several distinct types of programs. When speaking of "advocacy," people usually mean one of three things:

1. Individual advocacy, a one-to-one relationship between the individual in need of advocacy and the person who acts on his behalf.
2. Group advocacy, in which an individual or group is dedicated to, and represents, a cause which would benefit either an entire population or population sector group.
3. Ombudsmen roles, in which one person acts as an impartial investigator in settling complaints lodged by a citizen against a government agency.. The impartiality of an ombudsmen distinguishes him from a true advocate, whose perspective should be that of his client.

The public and voluntary agencies in the states of Pennsylvania, Ohio, Kansas, Wisconsin, and Nebraska were surveyed to identify existing advocacy programs for the developmentally disabled. Information was particularly requested on programs that provide individual advocacy. It was felt that under the time constraints

of this project information on individual advocacy programs would be more useful to the Minnesota Advisory Council than information on group advocacy. Most voluntary agencies have acted as group advocates for some time making that area both familiar and outside of the usual domain of state programs.

Kansas and Pennsylvania do not have existing individual advocacy programs for the developmentally disabled. Ohio and Nebraska each have functioning advocacy programs for the retarded that are run through voluntary agencies financed by federal funds in Ohio and state funds in Nebraska.

The Ohio program emphasizes advocates as friends for the retarded and provision of assistance in helping them develop independent living skills. It is expected that, as the advocates become more comfortable in their roles, they will also represent their retarded friends in dealing with service-providing agencies, protecting civil rights, and making sure that the retarded make use of all benefits available to them.

The Nebraska programs are similar to the program in Ohio. The composition of the staff is similar; two staff members are paid employees and the rest are volunteer advocates who work on a one-to-one basis with the retarded. The activities of the advocates are also similar; there is heavy emphasis on friendship and independent living skills. In the Lincoln site of the Nebraska program, advocates may spend more time working with service agencies, since they have been active longer. That is speculation on the part of program staff, however, since the Nebraska programs have little in the way of follow-up or evaluation.

The Wisconsin project was quite different from those in Nebraska and Ohio. It was a pilot project funded from the state's Public Health Services Act Section 314D Health Planning Grant to assess the feasibility of the Wisconsin Association for Retarded Children (WARC) setting up protective services on a statewide basis. Unlike the Nebraska and Ohio advocacy programs, the protective services project was staffed by two professionals who acted as advocates to 21 mentally retarded persons. Activities were centered more around legal and service-related problems and de-emphasized the friendship aspects of advocacy as compared to the other programs.

The differences in emphasis between the projects staffed by volunteers and the project staffed by professionals are illustrative of the impact that different types of workers have on a program. Non-professional voluntary workers generally result in closer, more personal contacts with clients, but at some sacrifice of impact on service-providing agencies and "helping" the client through the system. Where professionals act as advocates the reverse is true. The professionals are more willing to confront agencies; however, they generally work with a larger number of clients and some of the personal relationship is lost.

The one thing that the three programs have in common is that none of them is under the direct control of a public agency. All three are shielded by a private organization. Advocates of all types must because of their role be independent of the agencies or groups that they are trying to influence. If they are not, conflicts of interest will arise, making it impossible for the advocate to function effectively. Minnesota is in a favorable position to fund an advocacy program from Developmental Disabilities Act

money since the administrative body for implementing the Act is in the Governor's office and, therefore, somewhat separated from inter agency politics at the outset. Although no concrete evaluative data is available from any of the programs surveyed, it appears that the advocacy programs have been beneficial to the retarded personally and in terms of services received.

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APPENDIX A

INTERVIEW QUESTIONS

Description of Advocacy Services in Programs Dealing with Developmental Disabilities

1. Type of Advocacy

These lists are not comprehensive. Should a contact indicate one or more areas listed, the appropriate number can simply be circled; otherwise, write out the description in as much detail and in words as close to those that the contact used as possible.

a. Individual

1. Provide information to potential consumers of a service concerning the quality of that organization.
2. Provide information to a potential consumer concerning the type of services available.
3. Encourage persons to use existing community resources.
4. Inform persons about their legal rights of obtaining services from an organization.
5. Refer persons to community resources.
6. Act as an advocate for a specific person to insure that he is accepted for services, opportunities, and that he will obtain a reasonable benefit.
7. Follow-up persons referred to a resource to determine if the recipient is satisfied with the services and the result.
8. Other.

b. Agency

1. Getting an organization to modify or change legal but abusive and discriminatory policies, practices, and procedures (hiring restrictions, workmanship, overpricing, poor quality of services, etc.).
2. Working with an organization to insure that they abstain from illegal practices such as discriminatory acts, environmental abuses, etc. (e.g., legal compliance).

3. Provide consultation or technical assistance to an organization which will improve the performance of the organization.
 4. Raise funds for an organization.
 5. Assist similar or related organizations to plan cooperative programs, coordinate services, etc.
 6. Attempt to get legislation passed which would create new resources, improve funding, provide better regulation, improve services, etc.
 7. Other.
2. For each type of advocacy indicated in #1 find out:
- a. Who (type of staff member) provides the service and number of people providing.
 - b. Tasks involved in providing the service (in as concrete terms as you can pin the contact person down to).
 - c. Is money budgeted especially for this service? Source of funds?
 - d. Number of persons requesting the service last year (for individual advocacy).
 - e. Examples of problems, etc., that the clients had that led up to the service (both individual and agency).
 - f. Characteristics and numbers of the clients and organizations served, and what were their needs.
3. Impact
- a. What effect has the advocacy program had on disabled individuals? (This should be asked even if the program is strictly organization advocacy). How is this impact determined?
 - b. What effect has the advocacy program had on your organization?
 - c. What effect has the advocacy program had on other organizations and agencies? (Legislature and other government offices included.)

- d. What effect has the advocacy program had on public opinion?
4. It is assumed that the purpose of advocacy programs is to represent the "best interests" of the client. How are the "best interests" of disabled clients, particular the mentally retarded, determined by this contact?
5. What problems have come up in setting up and running the program?
6. What are the strongest and least effective points of your program?
Why?
7. What do you think are the advocacy needs of the developmentally disabled?
8. Do you know of any particularly effective programs for the developmentally disabled? Get address, contact person, etc.

APPENDIX B

PERSONS CONTACTED IN PUBLIC AND PRIVATE AGENCIES IN
OHIO, NEBRASKA, WISCONSIN, PENNSYLVANIA, AND KANSAS

OHIO

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Coordinator of Developmental Disability Planning
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Mr. James White
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Ms. Patricia Lertora
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Nebraska Department of Institutions
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Ms. Julie Meyerson
Office of Mental Retardation
Nebraska Department of Institutions
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APPENDIX C

PROTECTIVE SERVICES FOR THE MENTALLY RETARDED OF WISCONSIN

Materials received from the Wisconsin Association for Retarded Children.

WISCONSIN ASSOCIATION FOR RETARDED CHILDREN
351 W. Washington Avenue
Madison, Wisc. 53703

Protective Services for the MR of Wisconsin

Fact Sheet

I. INTRODUCTION

For many years parents of retarded persons have been concerned as to what will happen to their retarded son/daughter after they are gone. Who will be concerned for their needs and see that these needs are being met.

QUIET REVOLUTION stresses that every retarded person who needs Protective Services should have them, no matter what their age, degree of handicap, or financial resources.

The Wisconsin Association for Retarded Children feels that through their local associations they have the sincere interest and support for the mentally retarded and can and should become the agency providing the Protective Services to the mentally retarded of Wisconsin.

II. DESCRIPTION OF PROTECTIVE SERVICES

The following are potential services to be provided, leaving flexibility for additional services which might be later incorporated into the services:

1. Counsel adult mentally retarded and their families (friendship aspect).
2. Be the advocate for the adult mentally retarded and their family through and around "helping" systems.
3. Be the referral for the adult mentally retarded and their family to agencies and services with follow-up.
4. Give information concerning guardianship to the adult mentally retarded and their family.
5. Seek out adult mentally retarded citizens needing services.
6. Establish a continuous follow-up system. (A case is never considered closed.)
7. Observe and react to the unmet needs of each retarded individual to make sure appropriate services for each person is realized.

III. ADMINISTRATION OF SERVICE

The central administration officer for Protective Service is within the Wisconsin Association for Retarded Children. WARC would provide and deliver the service.

As the case load increases WARC would move to de-centralization. This would involve using WARC administrative districts. This approach would be advisable to insure -

1. Smaller amount of travel time to each client.
2. Help to provide more contacts per person.
3. Make for easy access to each person.

The Protective Services Coordinator would have PRIMARY responsibility for service and would be assisted by appropriate support personnel, the number to be determined by the number receiving the services.

Local ARC's would form an Advisory Committee to assist the Coordinator in delivery of the most appropriate service for their area's mentally retarded. The same Committee would also be used to evaluate the effectiveness of the services being provided in their area.

IV. ESTIMATE OF NEED FOR PROTECTIVE SERVICES

125,000 mentally retarded at various levels of impairment in Wisconsin are considered to have serious enough mental impairment to require care and treatment. Substance of this can be substantiated in that we have persons in three state mental hospitals, three colonies, thirty-five county hospitals, four private residential facilities for the retarded, and approximately 100 nursing homes that are providing care and treatment for these persons. The approximate population in these facilities is 16,000 and roughly 1/3 of these are 18 years old and older with sustaining disability requiring the need for long term or prolonged care.

Most persons in the 1/3 category are without adequate protection provisions to protect their civil /human rights. This fact creates administrative problems for those in charge of these persons.

V. CONTACT

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JJM 9/17/71

Wisconsin Association for Retarded Children

PROTECTIVE SERVICES DEMONSTRATION PROJECT

FINAL REPORT

August, 1971

Funded by
314-D
Division of Mental Hygiene

Katharine Ostrander, ACSW
Project Coordinator

Susanna Mooney, BA
Project Client Worker

WISCONSIN ASSOCIATION FOR RETARDED CHILDREN

PROTECTIVE SERVICES DEMONSTRATION PROJECT
FUNDED BY 314-D, DIVISION OF MENTAL HYGIENE

FINAL REPORT, AUGUST 1971

PREPARATION;

On April 5, 1971, Mrs. Susanna Mooney, Adult Protective Service Social Worker, and Mrs. Katharine Ostrander, ACSW, Project Coordinator, began work on the Protective Services for the Adult Retardate pilot project in Dane and Iowa counties. The first month was spend on procedural planning, project promotion, resource exploration, and the formation of a list of referrals from which to form the basic caseload of the project. With the recommended federal standard Protective Services for Children caseload of 15 to 20 in mind, it was anticipated that the basic service list would be about 20 cases with referrals evenly divided between the two counties.

1) Procedural Planning; The first need was an informational application form which would be filled out by the social worker on initial contact with the referred client and utilizing other appropriate sources of information. A three-page form was developed and printed with an attached release of information form on WARC letterhead, since it was recognized that many clients would already have essential medical, psychological, vocational, or social information on file with other persons or agencies. The unnecessary duplication of evaluative procedures or social studies was to be avoided as far as possible. A simple filing and record-keeping system was then set up, incorporating these forms and others such as case action narrative categories and a time record sheet. After studying the Protective Service categories in the new State Social Services case inventory system, it was decided to use the following headings to simplify recording:

ASSESSMENT: PROTECTIVE SERVICE TO ADULTS
Source of Referral Investigation
Evaluation Recommendation

SOCIAL SERVICE PLAN DEVELOPMENT: PROTECTIVE SERVICE TO ADULTS
Evaluation Procedure Counseling Program Change in Living
Conditions Training Program Financial Resource Referral

FOLLOW UP: PROTECTIVE SERVICE TO ADULTS

These forms were to be filed on the left hand *side* of the case **record** with correspondence and copies of evaluations on the right hand side. In addition, a file box was set up with basic information about each referred case, including the ones which were active. Record and file card models accompany this report.

2) Project Promotion: A general letter attached devised to give agencies and individuals a description of the proposed Adult Protective Services with an enclosed fact sheet about Mental Retardation was mailed on April 16 to 111 recipients in both counties, 94 in Dane which included 60 unit relief directors, and 17 in Iowa. The mailing list comprised public and private social service and health agencies as well as individuals known to be involved in programs for the retarded. Both before and *after* the mailing Mrs. Mooney and Mrs. Ostrander visited or telephoned the major agencies. Formal presentations of the service to be offered were given to both County Social Services' agencies, as well as less formal contacts with personnel. Mr. Gary Kuehnen of the Wisconsin State Department of Health and Social Services introduced the project and Mrs. Mooney to the Iowa County Department. Mrs. Mooney met with the WARC Advisory Committees

of both counties to describe the project and receive the benefit of their experience in the communities. She met with personnel at Central Colony, toured nursing homes, talked at length to groups of county nurses, and in general made herself and the project familiar to a variety of people and agencies in each county.

3) Resource Exploration; This activity was found to be carried on in conjunction with project promotion, since the hoped for source of referrals was often also productive of information about possible resources. The trips to county welfare departments and nursing homes, meetings with county nurses and Vocational Rehabilitation agents, talks with Development Evaluation Center representatives and MARC program planners, resulted in an exchange of information which laid the basis for evaluation, training and treatment referrals later.

3) Resource Exploration: This activity was found to be carried on in conjunction with project promotion, since the hoped for source of referrals was often also productive of information about possible resources. The trips to county welfare departments and nursing homes, meetings with county nurses and Vocational Rehabilitation agents, talks with Development Evaluation Center representatives and MARC program planners, resulted in an exchange of information which laid the basis for evaluation, training and treatment referrals later.

4) Referrals: Although our original request had stipulated May 1 as the deadline for referrals, we found this unrealistic. It was not until the third week of May that the basic caseload of 20 cases, later expanded to 21, was formed, although casework was already proceeding on several cases earlier. Eventually the file of total referrals showed:

TOTAL REFERRAL LIST - DANE COUNTY

Total Number = 35	14 - referred by the MARC Association
	10 - referred by the Dane County Public Health Department
	9 - referred by the YWCA
	2 - referred by private individuals

TOTAL REFERRAL LIST - IOWA COUNTY

Total Number = 34	22 - referred by the Iowa County Social Service Department
	8 - referred by the Iowa County ARC Advisory Committee on Protective Services or other members of WARC
	4 - referred by the Iowa County Public Health nurse

COMBINED TOTAL NUMBER REFERRED = 69

5) Basic Protective Services Caseload Of the 21 cases, 12 are from Iowa County and 9 from Dane County. Of the Iowa County cases 8 are referrals from the County Welfare Department while in Dane County, no referrals were received from this source. The cases shown for service from the total referral list were selected both to obtain a range of problems and because of immediacy of need, as indicated by the referral source. In order to demonstrate the type of problem these cases presented and to give some idea of the service which was given or planned, we are including a summary outline of each case.

6) Projections of Possible Need; Another facet of this project has been an attempt to make some determination of the possible present and future need for protective services in the two counties. In very round

6) (continued) figures, we found that there are now between 500 and 600 people in Dane County known to some agency or program as adult retardates Dane County retardates under 18 years of age who are connected with some form of service program are between 550 and 600 in number.

In Iowa County we found about 40 known retardates over 18 and about 60 under that age. The different relative size of the age groups in the two counties might be explained by the fact that Iowa County has very few resources for the adult retardate who thus tends to leave the county for training or residential care or otherwise drop out of sight. In Dane County there is the reverse situation where the resources actually bring in an appreciable number of persons in the older age bracket.

Adding the totals of the under 18 groups in both counties, we arrive at a figure of between 600 and 650 known potential clients for adult protective services. At this point, we have no means of estimating the number of retardates not known to any group or system.

PUBLICITY AND PUBLIC AWARENESS ON PROTECTIVE SERVICES

The WARC demonstration grant concerning Protective Services for the adult retarded in Iowa and Dane Counties has received much publicity.

At the onset of the project Robert Albrecht, District Administrator, Division of Mental Hygiene in consultation with Jayn Wittenmyer, WARC, drafted a statewide release on the grant project. Mr. Albrecht then sent the release to eighty-two radio and television stations, 275 weekly newspapers and 43 daily newspapers. Through the WARC clipping service we secured many newspaper articles on the grant from all sections of the state.

Enclosed with this report are the WARC News bulletin which carried an article on the grant as well as national newsletter which picked the article up from the WARC News bulletin.

WARC has received requests for information on Protective Service from numerous state and national agencies and organizations including the President's Committee on Mental Retardation; National Association for Retarded Children - On the Job Training (Project and Residential Services Staff; Executive Director of State ARC's in Indiana, Washington, New Mexico, Nebraska, Ohio, Pennsylvania, Minnesota and Oklahoma; Massachusetts Regional Administrator for Mental Retardation; Tennessee State Retardation Programs Coordinator; and the Arkansas State Coordinator of Special Services, Dept, of Social and Rehabilitative Services.

During the demonstration grant period, many local ARC's received general information on Protective Services. However, since the project has been getting publicity/many local ARC's have requested speakers on the service and demonstration findings during the next several months.

Publicity and Public Awareness on Protective Services (continued)

Public awareness on Protective Services has also been apparent in all of the letters, contacts, etc. which have been made with the numerous county agencies and organization persons by the Protective Services' staff.

Regional staff of the Division of Family Services and District Staff of the Division of Mental Hygiene have *been included* in information meetings and progress reports of the service.

COMMITTEE WORK OF PROTECTIVE SERVICES

During the demonstration grant period, Advisory Committees for Protective Services have been established in the Iowa and Dane County ARC's. The committee membership includes parents with various levels and ages of mentally retarded persons and other interested citizens from each county.

The Advisory Committee's purposes include input and evaluation of Protective Services geared to their own counties specific needs. Names of potential Protective Service clients have also been received from committee members. We see the Advisory Committees in local ARC's as becoming the citizen advocates for the adult mentally retarded of Wisconsin.

The WAPC Guardianship Committee, chaired by Colleen Roach, an attorney from Milwaukee, has taken a very strong interest in Protective Services. The committee and Protective Services' staff have met and the committee has expressed a strong desire to be direct advisory consultants to the staff of Protective Services.

As you will note from the Client Report section of this evaluation report, the parents or guardians of adult retarded persons have many questions and fears concerning, "What will happen to their retarded son/daughter after the parents are gone?"

The Guardianship Committee has agreed to prepare a booklet on guardianship, wills, trusts, etc. to give to parents to use in preparing for the future of the handicapped person.

The Guardianship Committee is very interested in continuing contact with the Protective Service staff as they see many strong implications for the two to work together.

EVALUATION

In reviewing the referrals and case activity, we find that the major needs which we have been called upon to fill have been ones largely outside of or in the gaps in current organized systems. That is, much activity of the worker went into investigation of reported situations and arrangements to get the clients to or at least into contact with available resources. In shorter form, this could be labeled "client recruitment," an activity few public social service systems are currently able to undertake to purchase. Frequently the worker found herself interpreting information for one agency from another and, indeed, performing an essential message-carrying function which can be labeled "coordination of services" if it is sufficiently successful. She found herself giving information and informal, friendly support and reassurance to several families who did not now need more, but certainly needed that much. Client advocacy within and to formal social welfare systems was an essential service which was evidently needed. Finally, in every case the need for continuous, consistent knowledgeable follow-up services was clearly noted. There were two overwhelmingly evident specific needs of our clients to which no special agency or group has yet addressed itself: legal advice and action and specially designed and trained foster care for the adult retardate. Complete written descriptions of residential treatment and training programs for retarded persons throughout the state were also largely lacking.

From the services required from us to date on this project and from the difficulties we often experienced in delivering them, we conclude that Protective Services for the Adult Retardate is definitely a valuable program, one that should be continued and expanded within the framework of

EVALUATION (continued) a private agency which is client-centered rather than system-maintenance focused. The activities which Mrs. Mooney carried out, although recognized by the public social service systems as valuable, are not in fact most of them being performed by these systems which do not at this time possess the necessary freedom in time, money, and conception to seek out clients and pursue their welfare along the intricate paths of existing resources

Therefore, we make the following recommendations:

1) WARC should continue its Protective Services program on an independent basis, recognizing that the vital services which it can perform for the adult retardate are not at the present time feasible purchasable items by county systems.

2) The following specific programs and services should be consciously developed by WARC to be used as basic tools of the program:

a) A Legal Committee which will furnish advice and legal counsel throughout the state and will provide suitable Legal Guardians as needed for adult retardates; a basic handbook of legal information and advice should be compiled by this committee for general use.

b) A foster home recruitment program on a statewide scale with a carefully current list of available homes; training programs for foster parents might be held in connection with this program.

c) A comprehensive, continuous, up-dated survey with accompanying descriptive manual of various services available to retarded adults throughout the state; a special section in this book should be devoted to existing residential facilities with details such as location, type, size, cost, programs, community services available, professionalism of staff, etc.

d) The development of planned communication and rapport with such systems as Development Evaluation Center and Division of Vocational Rehabilitation so that follow-up services of referrals and recommendations can be given promptly and the flow of information can be maintained.

e) The local ARCs be considered in to as advisory councils with one person as the contact agent with Protective Services; the function of the ARCs as pressure groups in each county to see that protective services are available for adult retardates should be explored

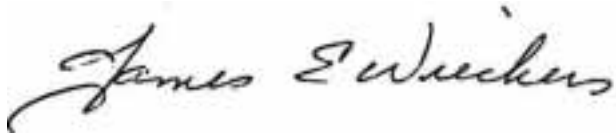
Developmental Disability Plans
- A FIVE-STATE SURVEY -

Prepared for the EXECUTIVE
OFFICE OF THE GOVERNOR STATE OF
MINNESOTA

By the
Institute for Interdisciplinary Studies
. 123 East Grant Street
Minneapolis, Minnesota 55403

December 20, 1971

Approved for
INSTITUTE FOR INTERDISCIPLINARY STUDIES

A handwritten signature in cursive script, reading "James E. Wiechers". The signature is written in dark ink and is positioned below the typed name.

James E. Wiechers, Ph.D.
Director
Educational and Occupational Research Division

DEVELOPMENTAL DISABILITY PLANS

- A FIVE-STATE SURVEY -

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SUMMARY

Five states were surveyed to determine their planning and implementing of programs dealing with developmental disabilities. Public and private agencies in Kansas, Nebraska, Ohio, Pennsylvania, and Wisconsin were asked to describe the information sources on which they relied and to evaluate the reliability and usefulness of the information obtained. Each state also provided information on the organizational structure of its developmental disabilities program and its future plans.

Information Systems

Most states reported that their information systems were inadequate and that they were making improvements. The most common weaknesses reported were (a) insufficient data or insufficiently centralized data files pertaining to the actual incidence of developmental disabilities in a state, and (b) excessive reliance on relatively unsubstantiated percentages in estimating state or local incidence of developmental disabilities.

Kansas took a door-to-door census as a pilot program in one county to determine the incidence of developmental disabilities. A statewide door-to-door census is being considered. Poverty areas in the state have been identified.

Nebraska uses established incidence and prevalence rates to estimate need and compares this estimate with numbers actually being served to estimate unmet need. By the end of 1972 a centralized information system is expected to be in operation, utilizing information collected by 23 public and private agencies. Poverty areas have been determined.

Ohio relies on global estimates for its incidence figures. These are applied to population figures in each county to make territorial

estimates of incidence. Local programs have fairly good information on the characteristics of clients. At Ohio State University some efforts have been made to centralize this information, but parents' reluctance to share information has been an obstacle.

Pennsylvania has a central file of patients served by state agencies, with provisions for monthly up-dating. Analysis of data provides demographic characteristics of clientele of each service unit as well as information on staff and caseloads, type of service, and data on terminated cases.

Wisconsin has detailed estimates of incidence, based on work done by the California Study Commission on Mental Retardation, as applied to Wisconsin census data. A computer system processing information on all persons known to school authorities is expected to yield useful incidence data when it has been in operation longer. There is a sharp divergence of estimates of unmet need made by the state and by the ARC. Wisconsin has done extensive work on developing a priorities system based on weighted indicators.

Organizational Structures and Future Plans

Kansas: The designated agency for administration of the state plan is the Division of Institutional Management, under the State Department of Special Welfare. The State Council plans to develop regional councils, and emphasis of the program is to be on the filling of gaps in the delivery system of community services.

Nebraska has a State Planning and Advisory Council that includes representatives of governmental and non-governmental agencies and of the public. General goals have been set, but no details have been spelled out. A concentrated effort is being made to obtain special funding for programs in poverty areas.

Ohio has an Advisory Council. Administration of the plan is under the Division of Mental Retardation in the Department of Mental Health and Correction.

Pennsylvania: The Department of Public Welfare has been designated as the state agency until a permanent advisory council is appointed and recommends location of permanent responsibility. First year plans emphasize assessment of need for existing resources and the development of a comprehensive state plan. Consultants at Pennsylvania State University were engaged in October 1971 for a preplanning study to identify information needs and methodology, and to make preliminary estimates on incidence and available services by geographic areas.

Wisconsin: Pending legislative action, the Division of Mental Hygiene within the Department of Health and Social Services has been designated the agency for administration of the state plan. The Council on Facilities for Mental Retardation is serving as interim council.

DEVELOPMENTAL DISABILITY PLANS

To assist Governor Wendell Anderson in developing the Minnesota State Plan under P.L. 91-517, the Institute for Interdisciplinary Studies (IIS) has conducted investigations of developmental disability programs in five other states. This report, one of three prepared by IIS for the Office of the Governor, describes the methods of collecting information in those five states for programs dealing with developmental disabilities.

It is necessary, of course, to have data on the incidence of developmental disabilities and to know what services are being provided in order to project the unmet need. Systematic information is needed for each of the following stages of program development:

- setting goals, based on unmet need;
- setting priorities, based on order of need;
- allocating resources; and
- measuring progress toward the goals.

Beyond these general purposes the need for specific details of information are illustrated in the forms provided for filing the 1972 State Plan for Developmental Disabilities. For example, attachment 5.2B to the State Plan asks for the order of need for services, broken down by geographic area. Sixteen specific services are listed, including diagnosis, treatment, and various kinds of care and training.

Attachment 5.2A asks for the number of persons served in existing state programs, broken down by disability; it also asks for the

types of services provided by each program. These data are not consistently available from the agencies or departments, whose record keeping methods vary considerably. Furthermore, a footnote to this portion of the state plan specifies that the quality of services provided be in accordance with "applicable standards and regulations." This could be interpreted to mean that evaluative measures would have to be applied to each service provided by each agency. A civil rights clause might be interpreted to require information on race, color, or national origin of persons served.

It can be seen, then, that the complexity of needed information is far beyond what is presently available, and the Council will have to explore techniques for collecting and centralizing information, as well as for encouraging public and private agencies to develop a greater degree of sophistication in their own information systems.

To help provide a background for the Council's efforts in the area of information collection, public and private agencies in the states of Kansas, Nebraska, Ohio, Pennsylvania, and Wisconsin were asked to describe their data sources and to evaluate the reliability and usefulness of the information obtained. Particular attention was given to the following:

- rate of incidence of developmental disabilities;
- general population characteristics;
- client characteristics; and
- service needs.

Telephone interviews were conducted with representatives of appropriate agencies in the five states selected for study. (The structured interview that was used can be found in Appendix A.

Appendix B is a list of agencies and individuals contacted.) Information was requested with respect to the kinds of information being collected, the sources of information, and the overall quality of information. In addition to information provided during the telephone interviews, written documents giving details of their programs and plans were also obtained from some of the agencies contacted.

In most cases, contact was made by IIS staff with at least one public agency (the one designated by the state as having administrative responsibility for the developmental disability program at the state level), and one private agency (generally the state-level Association for Retarded Children). The results obtained were not exhaustive, due to time and resources constraints, but they are believed to reflect fairly the relative status of information utilization across these five states.

All states recognize that they were in less than an ideal position with regard to information-collection activities. In general, they were dissatisfied with their first-year plans and were attempting in varying degrees to remedy defects. However, sufficient time has not yet elapsed for these efforts to yield results.

Information sources used by the five states included:

- census data;
- global estimates of incidence;
- systematized data generated by state agencies;
- reports filed by projects;
- periodic surveys; and
- statewide information systems.

No one state used all these sources. However, most states did have certain generally accepted estimates and expressed some reliance on census data. No state reported any activity in developing resource allocation procedures. Most were at the point of considering the major issues in the ordering of priorities, but none had completed this particular task. Pennsylvania has centralized files on patients served, with an ongoing system for analysis of the information. In Nebraska the development of a centralized information system is in progress. In Wisconsin procedures for determining priorities are now being developed.

A typical weakness among most states is that information on the disabled population is not centrally compiled. Planning on a statewide basis is often done on the basis of global estimates that are not very useful for determining the service needs of the target population. It is difficult to infer anything about how well the service needs of the population are being met from scattered information on clients served by various, possibly overlapping agencies in the state and only a rough estimate (based on a global estimate of two or three percent) of how many people with disabilities exist.

The remainder of this report consists of state-by-state summaries of the results obtained from the project survey. Appendix C is a bibliography of selected materials that should prove useful to those involved in activities in this area. Appendixes D, E, and F are printed materials provided by the states of Nebraska and Wisconsin.

I. KANSAS

A. Organizational Plans

The Division of Institutional Management of the State Department of Social Welfare is the designated agency for administration of the Kansas state plan. This division also is responsible for four institutions for the mentally retarded and for community planning and coordination of services for the mentally retarded. The State Planning and Advisory Council is made up of representatives of governmental agencies, which include the departments of Welfare; Labor; Vocational Rehabilitation; Vocational Education; Health; Special Education, Board of Regents; University of Kansas, Board of Regents; the Office of the Attorney General; the Crippled Children's Commission; and "consumer" representatives from various private organizations and agencies.

The position of Planning Director has not yet been filled. Additional staff may also be hired. Plans call for federal expenditures of about \$205,000 for fiscal year 1972; the largest portion of this money will be spent on services.

B. Available Information

Planning for the state was based upon eleven areas or regions. Estimates were made of the total number of developmentally disabled people in each region and of the number now being served (not including those served in public schools).

Poverty areas in the state were also determined using the following factors:

- percent of families with incomes under \$3,000;
- percent of population receiving welfare assistance;
- unemployment rate; and
- infant mortality rate.

The method by which these factors were combined was not described. Virtually all of the counties in the state are described as being poverty areas.

Each of the other federally assisted statewide programs also estimated the numbers of persons who are mentally retarded, or who were afflicted with cerebral palsy or epilepsy.

In the private sector, the Association for Retarded Children was contacted. This association and the United Cerebral Palsy Fund conducted a survey of the facilities serving developmentally disabled clients. These included day care centers, public schools, preschool facilities, adult facilities, and private and public residential facilities. The methods used included questionnaires, telephoning, and personal visits. The surveys were considered highly successful and the information is considered to be of high quality. All this information is used to plan and redirect services by the Association for Retarded Children.

A pilot project in one county of the state of Kansas is currently under way, utilizing a door-to-door census to obtain information on incidence rates. Client characteristics were generally obtained by age, sex, and type of disability. The same procedure is being considered for gathering information to support legislative proposals. State-level information, however, was not found to be very useful.

Information on service needs coming from the local level seems to be on a rather informal basis. A general need was expressed for information on local levels.

C. Future Plans

The State Council intends to develop regional developmental disabilities councils representing public and private agencies and consumers. These councils are to work with the existing comprehensive health-planning councils and other groups to meet the needs of the developmentally disabled. The Council intends to emphasize the filling of gaps in the delivery systems of community services.

Appendix H contains a listing of the goals and objectives and the projects to be funded in fiscal year 1972.

II. NEBRASKA

A. Organizational Plans

A number of state agencies in Nebraska are involved in providing services for the developmentally disabled. These are shown in Figure 1. As in other states, representatives of these agencies and the major nongovernmental organizations and groups are brought together with a group of consumers to make up the State Planning and Advisory Council. The planning director of the council is a full-time employee. In addition, there are three other staff positions.

B. Available Information

Unmet need is determined by analyzing the data that are available. Planners in Nebraska use established incidence and prevalence rates to estimate the number of developmentally disabled persons who should need services at a given point in time in each geographic planning area in the state. These figures are compared with the number of disabled actually being served, which is ascertained through a survey of facilities that serve the developmentally disabled. Each planning area can then be described according to the number or proportion of the developmentally disabled with unmet needs.

An effort is being made in Nebraska to become eligible for special funding for poverty areas. A procedure was worked out to determine which counties in the state had the highest concentrations of poverty. A description of these procedures is included in Appendix E. The most significant considerations include proportions of the population over 65 years of age, families with female heads and children under 18, housing that lacked plumbing or kitchen facilities, housing with more than one person per room, and unemployment rates.

Figure 1

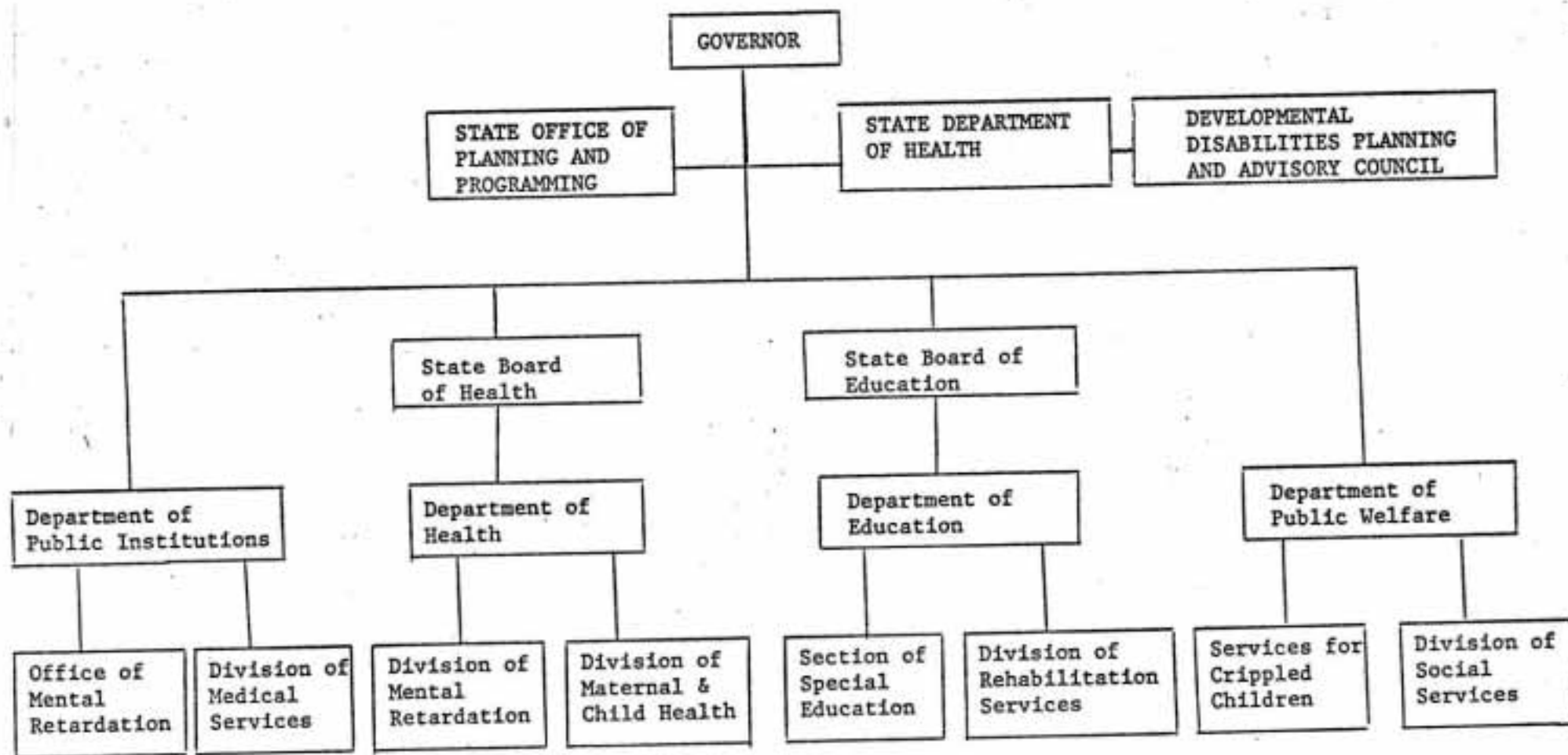


FIGURE 1. STATE AGENCIES INVOLVED WITH DEVELOPMENTAL DISABILITIES

C. Future Plans

A general goal has been established in keeping with the federal guidelines, but no absolute levels of performance has been established in Nebraska as goals for the year. All programs must meet the general goal established by the Planning and Advisory Council: "Services for the developmentally disabled must hold significant promise toward the alleviation of a developmental disability or toward the social, personal, physical, or economic rehabilitation or habilitation of such individuals."

General goals for services mentioned in the plan are as follows:

1. Diagnosis, evaluation, and services for early childhood intervention;
2. Day care (training, education) and long-term sheltered employment;
3. Transportation;
4. Domiciliary alternatives to institutional care (special living arrangements);
5. Information and referral systems;
6. Special provisions in generic service-delivery systems (recreation, counseling, protective, and follow-along services).

Concentrated effort is to be directed to the areas of greatest need. Nebraska has followed much the same procedure as other states in attempting to rank of regions according to their needs for services. A description of these procedures is included in Appendix D.

Some of the problems involved in translating statistical information into allocation decisions were pointed out by people in several government agencies in Nebraska. The Office of Mental

Retardation in the Department of Institutions indicates that the survey of resources and needs of the mentally retarded and the reports it has generated are not yet as useful as the global estimates that are traditionally relied upon, although these reports are currently under study. The Office of Health Planning reports a similar reaction to these studies, although they are using the information as part of their efforts to establish a central data file on the disabled population in the state.

Some 23 public and private agencies in Nebraska have been identified as collecting information about the disabled children in the state. A project, scheduled to be fully implemented by the end of 1972, will centralize this information; developing a standardized information format with more precise definitions of categories of disability will permit better planning and programming. It will then be possible to learn more about what areas of the state are in need of new or expanded programs, and what resource allocation is needed. Federal, state, and local agencies will be able to obtain information that will aid in the delivery of comprehensive services to disabled children.

III. Ohio

A. Organizational Plans

Coordination of planning for the developmentally disabled is administratively housed in the Division of Mental Retardation in the Department of Mental Hygiene and Correction. The Advisory Council is established along the lines specified in the Act with participation by state agencies, nongovernmental agency representatives, and consumers.

B. Available Information

The incidence of epilepsy, mental retardation, and cerebral palsy is estimated by global estimates of incidence. Epilepsy is estimated to afflict two percent of the population. Cerebral palsy is estimated to afflict 0.2% of the population under age 21 and 0.1% of the population age 21 and over. The total estimate of persons with cerebral palsy is approximately 0.14% of the population of Ohio (15,000 out of 10,600,000). Estimates of mental retardation are made by level of retardation and age as follows:

	Mild	Moderate	Severe	TOTAL
younger than six	1.0%	.4%	0.1%	1.5%
six to 20	2.5%	.4%	0.1%	3.0%
21 and over	0.5%	.4%	0.1%	1.0%

These estimates are applied to the population in each county to estimate the eligible population on a territorial basis. It is recognized by the persons involved that this method is inadequate, but it is the only means at hand. However, there does appear to be some effort in the Cleveland area, begun in November, to accumulate data about the epileptics in the area.

The Association for Retarded Children is beginning to develop a registry of the mentally retarded who require continued care. While this is still incomplete, approximately 400,000 mentally retarded are estimated, and 82,000 are now being served.

Additional information comes from the mental retardation training program at Ohio State University. County boards in mental retardation provide information on the severely retarded (I.Q. below 50). It is estimated that 20,000 severely retarded or retarded but trainable persons are served in some kind of program in the state, and an additional 9,800 are in the six state institutions for the mentally retarded.

At the county level, the local programs have fairly good information on the characteristics of clients.

C. Future Plans

The 1969-1970 State Mental Retardation Plan specifies the service need, by county, for both young and adult retarded persons. Ohio has not yet taken the additional step of compiling local information in a central data file, although there is some activity along this line at Ohio State University. A principal stumbling block appears to be parents' reluctance to have information about their retarded children made public to any extent.

IV. PENNSYLVANIA

Much of the information for the State of Pennsylvania was obtained from the state plan submitted for the year 1970-71, and the state's Mental Health and Mental Retardation Act of 1966, which set up the state's county mental health and mental retardation program.

A. Organization Plan

The designated state agency for the Developmental Disabilities Program is the Department of Public Welfare, until such time that a permanent advisory council is appointed and gives the Governor its recommendations on the ultimate location. The major thrusts of the first year are to be planning and assessing the need for existing resources, and developing a comprehensive state plan.

B. Available Information

The Mental Health and Mental Retardation Act of 1966 provided for the maintenance of central files for each patient by the service project. This record includes:

1. The history of movements of the patient through the services provided directly by the service unit, as well as those services provided to him by the county program; and
2. Progress notes.

Further reports, including monthly contact reports, are to be filed by the service unit. These reports are to be submitted on a monthly basis. An analysis is provided by the department for each service unit and for the county as a whole. This analysis according to the unit provides information such as:

1. Demographic characteristics of the clientele of each service unit, to be compared with the demographic characteristics of the population being served.

2. Current staff of each service unit; caseload by age, sex, diagnosis, time since intake, types of services, and so on.
3. Data on cases terminated by diagnosis, number of services unit provided; by whom, what type, cost per case, time per case, and so on.
4. Other special studies.

Provision was also made in the 1966 act for evaluation of the projects.

C. Further Plans

In October, 1971, negotiations were conducted with consultants at Pennsylvania State University for a preplanning study for developmental disabilities. The objectives of this study are:

1. To improve the definition of the field of information that will have to be developed and analyzed in a more intensive planning activity.
2. To identify the conceptual issues and methodological problems of data collection and analysis to be dealt with in such a study.
3. To produce preliminary estimates on three significant data areas:
 - a. the incidence of developmental disabilities including such areas as mental retardation, cerebral palsy, epilepsy, learning disabilities, and other types of neurological and other problems in various sections of the commonwealth;
 - b. the characteristics of these populations to the extent that they can be determined from existing data pools; and
 - c. the resources that are reported by public and private agencies as being available to these populations.

V. WISCONSIN

A. Organization Plan

In the State of Wisconsin, the Department of Health and Social Services (see Figure 2 for schematic diagram) is a designated agency for the administration of the state plan and administration of grants for construction. The Governor has designated the Council on Facilities for the Mentally Retarded to serve as the interim council on developmental disabilities, pending legislative action. The Division of Mental Hygiene within the Department of Health and Social Services is primarily responsible for the program (see Figure 3). Within that particular division, the following bureaus have been given these responsibilities:

1. Bureau of Planning - Evaluation Research:
 - a. assisting in the staffing of the council;
 - b. developing a state plan, including:
 - (1) Information systems (involving designing and conducting inventories, revising or developing reporting systems, and collecting other information from other state programs),
 - (2) priority system based on relative needs;
 - c. examination of aspects of the program.
2. Bureau of Mental Retardation:
 - a. serving as a consultant to the council;
 - b. cooperating in developing a state plan;
 - c. administering the state plan.
3. Bureau of Community Resources:
 - a. informing eligible agencies about the program;
 - b. assisting in developing and processing applications;
 - c. submitting critiques of processed applications;
 - d. assisting in the monitoring of evaluation functions.

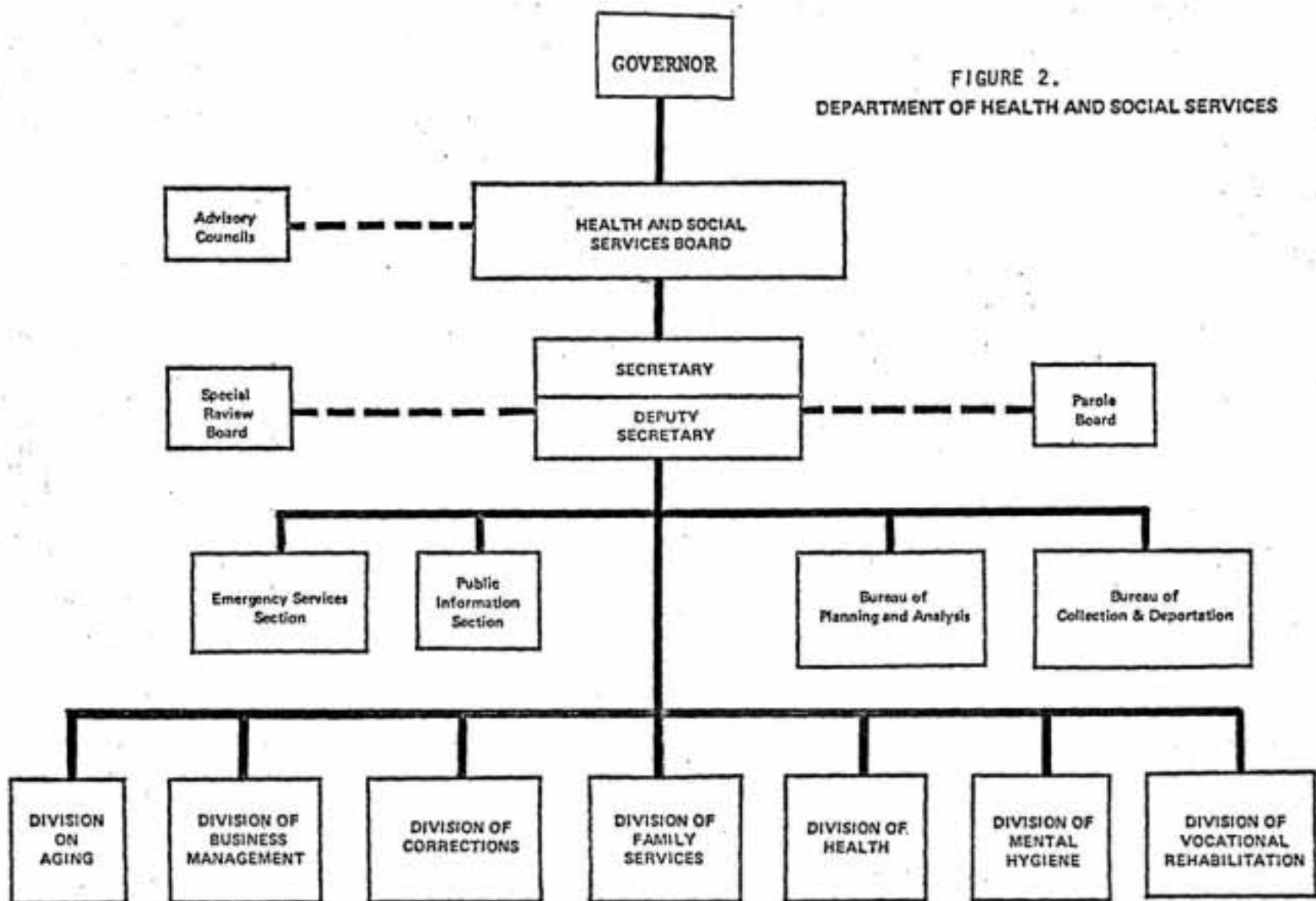
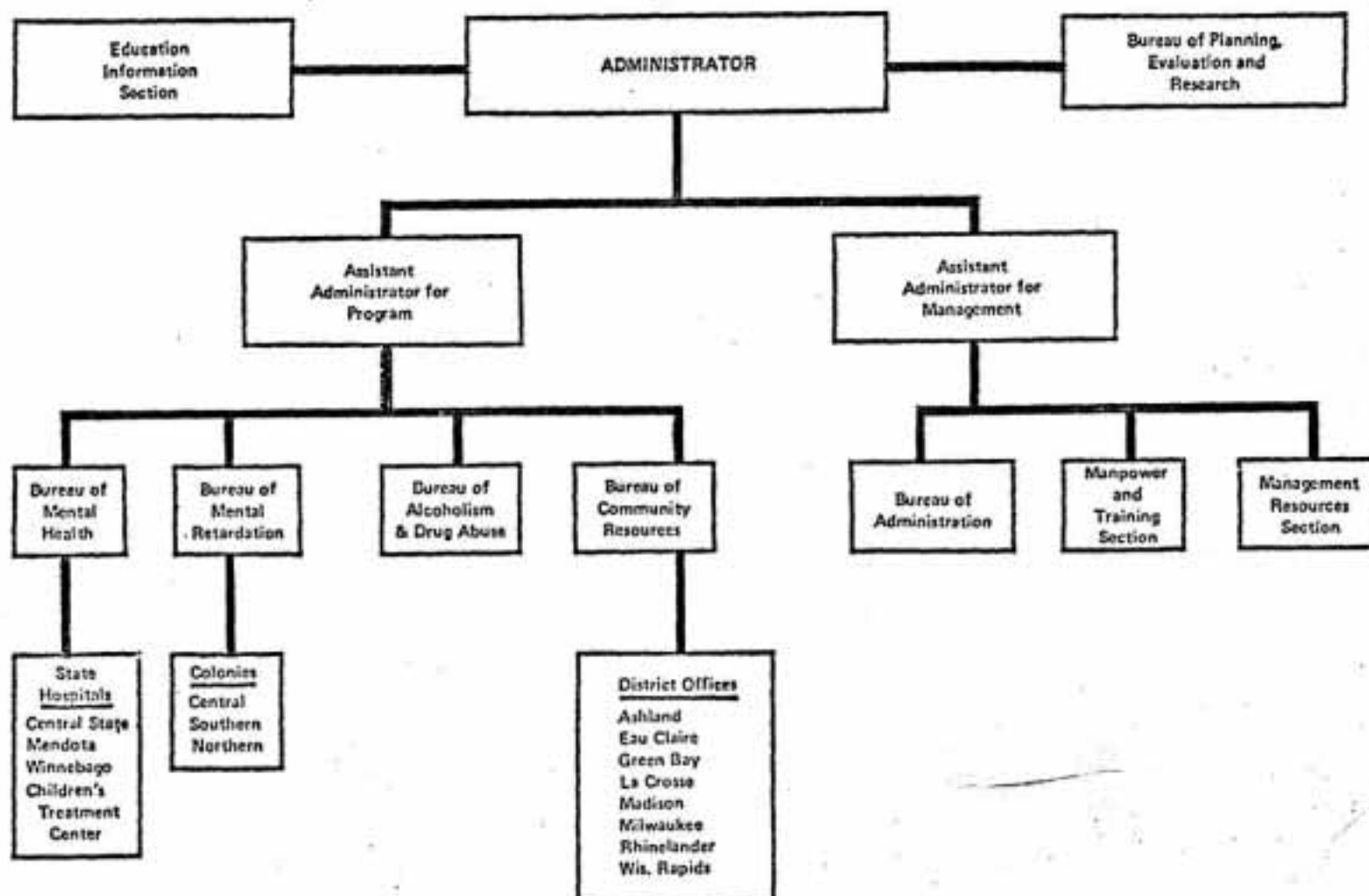


FIGURE 2.
DEPARTMENT OF HEALTH AND SOCIAL SERVICES

FIGURE 3.
DIVISION OF MENTAL HYGIENE



B. Available Information

The state has estimates of the incidence rates for mental retardation and other conditions applying to mental retardation, cerebral palsy with mental retardation, epilepsy with mental retardation, cerebral palsy (alone), epilepsy (alone), childhood schizophrenia, all other mental problems of the nervous system, and sensory physical disorders (muscular, etc.). These estimates were based upon an in-house report (Appendix G), which was in turn based upon work done by the California Study Commission on Mental Retardation and the census estimates for the state of Wisconsin. The result was an estimate of approximately 1.9%; this was considered the most appropriate figure for the developmental disabilities program. This is contrasted with the usual 3% figure generally given and used by other agencies. The reasons given for this disparity were that:

- borderline cases are not represented, since they are being interpreted as not being included in the program; and that
- the 1.9% represents rates of prevalence – those individuals having developmental disabilities at a given time – as opposed to incidence rates of those individuals who will experience developmental disabilities sometime during their entire lifetime.

The Wisconsin Association for Retarded Children (ARC) uses a 3% estimate for mental retardation. The limitations of this estimate are recognized and a desire was expressed for a more updated incidence rate. Particular discrepancies have arisen with the Educational Association estimate. The ARC stipulates that 40% of the needs of retarded children are being met, while the state claims 92% are being met. Both figures are admittedly extremes.

The Division of Handicapped Children is working on a computer system to attempt to obtain up-to-date information on all persons

known to school authorities. The system is already in operation but not yet advanced enough to give feedback on incidence.

The central office of the local ARC has never tried to compile the characteristics of clients served. A rough estimate of the number served last year was given as approximately 8,000.

Service needs are generally taken from state estimates. The state of Wisconsin publishes a yearly report of the primary needs of the developmentally disabled by each district.

C. Future Plans

There is a capability for the analysis of the primary service needs of persons with developmental disabilities in each of Wisconsin's districts. This analysis will be primarily based upon the reports filed by the various developmental disabilities projects.

Wisconsin has established goals for the developmental disabilities program. It has also made progress in the designing of a priorities system. To measure relative need and to rate proposed projects, it has been found necessary to develop a method for selecting and weighting indicators. This is now in progress. The indicators proposed for council consideration are categorized into three groups.

1. Indicators of relative need – to be used to determine the priority for construction projects:
 - a. percent of need met by type of service;
 - b. percent of need met by age group;
 - c. poverty ratio;
 - d. other area characteristics:

- (1) combined infant and fetal mortality rate,
 - (2) percent of unemployed,
 - (3) density per square mile.
2. Indicators for rating proposed service projects – to be combined with indicators of relative need to determine the priority of service projects:
 - a. resources of other funding programs to provide services;
 - b. capacity of project to meet widespread need, by type of service;
 - c. realism of budget, means, and methods;
 - d. evaluation of methods to be used.
3. Indicators for rating of planning projects – to be combined with indicators of relative need to determine priority of planning projects:
 - a. realism of budget, means, and methods;
 - b. adequacy of proposed planning process.

These indicators, together with proposed weighting schemes, are described in further detail in Appendix F.

APPENDIX A

Questionnaire – Description of Social Indicators
in Programs Dealing with Developmental Disabilities

Description of Social Indicators in Programs
Dealing with Developmental Disabilities

1. Do you have information on the incidence of developmental disabilities in the area you serve?
 - a. Would you describe the information you have and where it comes from.
 - b. How would you evaluate the quality of this information?
 - c. How would you describe the usefulness of this information to your agency?
 - d. Is there additional information about incidence of the developmental disabilities that would be useful to your agency?
2. What information do you have on the characteristics of the developmentally disabled in the area you serve such as information about age, sex, race, health, housing situation, educational status, and so forth?
 - a. What is the source of this information?
 - b. How would you evaluate the quality of the information?
 - c. How would you describe the usefulness of this information to your agency?

- d. What additional information of this sort would you like to have?
3. What kind of information on the service needs of the developmentally disabled do you have?
- a. What is the source of this information?
 - b. How would you evaluate the quality of the information?
 - c. How would you describe the usefulness of this information to your agency?
 - d. Do you feel it would be useful to have more information on the need for services of the developmentally disabled? What kinds of information?
4. What information on the characteristics of the people that you actually serve do you collect?
- a. What procedures do you use for obtaining this information?
 - b. Could you provide us with copies of the forms which are used?
 - c. How would you describe the usefulness of this information to your agency?
 - d. Do you feel it would be useful to have more of this type of information available?

5. What information does your agency use in making decisions about changing, expanding or redirecting the services which you offer?
 - a. What is the source of this information?
 - b. How would you evaluate the quality of this information?
 - c. How would you describe the usefulness of the information for planning agency activities?
 - d. Do you use such indirect items as population census, per capita income, availability of health manpower, etc., in determining changes?
6. It is reasonable to suppose that your agency has some information needs which are not presently being met. In as much detail as possible, could you describe the kind of information you would like to have to improve the planning or evaluation of your activities.
7. Taking everything into consideration, how adequate do you feel the information used by public and private agencies which provide services is for planning and resource allocation purposes?

APPENDIX B

PERSONS CONTACTED IN PUBLIC AND PRIVATE AGENCIES IN
OHIO, NEBRASKA, WISCONSIN, PENNSYLVANIA, AND KANSAS

OHIO

Ms. Carolyn Knight
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Mr. Baird Krueger
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Mr. James White
Ohio Association for Retarded Children
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2337

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Ms. Julie Meyerson
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Mr. Peter Peshack
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Ms. Jayn Whittenmyer
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608-256-7774

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Pennsylvania Association for Retarded Children
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KANSAS

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Mr. Dennis Popp
Coordinator of Developmental Disabilities Planning
913-296-3473

Ms. Gloria Wright
Kansas Association for Retarded Children
913-236-6810

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APPENDIX D

Procedures for Determination of Priorities among Regions, State of Nebraska, from the State Plan: Developmental Disabilities Services and Facilities Construction Act of 1970 (Public Law 91-517)

ATTACHMENT 5.4D DETERMINATION
OF PRIORITIES AMONG REGIONS *

The purpose of this section is to describe the priority system and methods of calculation by which the relative needs of the developmental disabilities planning regions are derived. It is necessary to establish a priority system to insure that regions, with the greatest need for services receive the first opportunity to obtain Federal grant funds. Based on the most available current information, a statistically-sound priority system was used to determine the relative need for services in the regions. (Refer to page 58 for a Regional Map and an explanation of the regional structure).

A. Section of Indices

Three major categories of indices were used to determine the relative need and priority ranking of regions. The categories are:

1. Population characteristics.
2. Socio-economic characteristics.
3. Mental retardation, Cerebral Palsy and Epilepsy resources.

These three indices reflect the extent of developmental problems and the availability and accessibility of resources.

In selecting the indices of need, consideration was given to the following factors:

1. Indices had to be comparable throughout the State.
2. Indices had to be based on information from reliable and objective sources.
3. _____ Data collected had to be reported on a county basis,
_____ thus the reporting base would be the same for all indicators.

* Survey of Resources and Needs of the Mentally Retarded With Special Problems, Bill Hinze, Statistician; June, 1971.

4. Only those indices that evidenced great stability overtime, thus negating a distortion caused by rare events, would be chosen.

B. Explanation of Priority System

A definition of each indicator, the reasons for selecting it, the source of the data, and the weighting and ranking systems are presented on the following pages.

1. Population Characteristics.

Four variables were selected in this category: population density, rate of population change, percent of population under .15, and percent of population living in rural areas.

Low population density, coupled with an absence of developmental resources, indicates a high need for expending services and developing additional manpower. This is particularly true in a state like Nebraska which has a disproportionate distribution of services favoring the high population areas. Population density is defined as the average number of persons per square mile. This figure is determined by dividing the 1970 population of an area by the number of square miles in the area.

Rate of population change refers to the percent of change in population for each region from 1960 to 1970. The percentage for each region was calculated from county rates. This variable would indicate change in population distribution and give evidence of those areas in the greatest state of flux.

The percent of population under 15 years of age was included in this category. It is felt that programs serving this age group are of significant importance in the long run to the adjustment and development of developmentally disabled persons in adult life. A percentage for each area was calculated on the basis of county or census tract rates.

The fourth variable chosen was the percent of population living in

in the accessibility of services. In predominately rural areas, it is often difficult, if not impossible, to obtain services due to the great distances that must be traveled. This factor points up the need for services located outside the larger population centers. The percentage was calculated for each region based on county or census tract rates.

The source of information for all variables in this category was the United States Census of Population, PC-29-Nebraska, 1970.

2. Socio-economic Characteristics.

Six variables were selected in this category:
percentage of households with low income,
percentage of housing lacking some or all plumbing
facilities, percentage of overcrowded housing, rate
of unemployment, rate of persons receiving A.D.C.,
and rate of infant mortality.

Percentage of households with low income is defined as all families and unrelated individuals in the region with income of under \$3,000 per year. There is evidence that developmental disabilities are often associated with poverty. The poor are generally the least able to purchase or utilize the available services, especially in rural areas, because of lack of transportation to programs. It must be remembered that poverty is not limited to large cities, but is also prevalent in rural areas. A percentage for each region was calculated on the basis of county rates. The source of this information was the Sales Management Corporation Survey of 1970. Due to the date of completion of this report, it was not possible to obtain figures from the United States Census Bureau of 1970. Therefore, the use of data from other recognized and reliable sources was made necessary; for example, Sales Management Corporation.

The percentages of housing lacking some or all plumbing facilities and the percentages of overcrowded housing were used as indicators of low-quality or substandard housing. These variables were selected as they

reflect general living conditions of the area. The percentage for the region was calculated based on county or census tract rates. Source of information was the United States Census Report, HC-29, Nebraska - 1970.

Recipients of A.D.C. (Aid to Dependent Children) indicates to some degree the economic and family disorganization in the region. A.D.C. recipients are commonly unable to obtain necessary services because of their economic status. The rate of A.D.C. recipients was determined by dividing the total number of recipients by the 1970 population of an area and then multiplying by 1,000 to obtain the rate per thousand. The sources of information were the Division of Research and Statistics, Department of Public Welfare, Nebraska - 1970, and the United States Census of Population, PC, 1970.

The unemployment level of the work force was the fifth variable in this category. The rate of unemployment indicates to a degree the economic conditions in an area. A high rate commonly means low family income; therefore, creating an environment of socio-cultural deprivation. Source of the information was the Nebraska Department of Labor, 1969.

Infant mortality was the sixth variable chosen in this category. Often a high infant mortality rate is a reflection of poor pre-natal and postnatal care and poor environmental conditions prevailing in the area, both of which influence directly and indirectly the prevalence of developmental disabilities. The source of information was the Annual Report, Nebraska Bureau of Vital Statistics, 1969.

3. Resources for the Developmentally Disabled.

The availability of public and private resources for the developmentally disabled is a major problem. This is especially true in a predominately rural state like Nebraska. The bulk of the facilities and manpower are located in the larger metropolitan cities in the eastern end of the State.

Attachment 5.1 describes the established methods of estimating the number of individuals in the State who are classified as Mentally Retarded, Epileptic, and/or Cerebral Palsied. Using the percentage figures defined, (1) an estimation of the total number of developmentally disabled in each region in need of service was determined, (2) the number of developmentally disabled already served in the region was ascertained through a complete survey of all known facilities serving the developmentally disabled, and (3) the number of developmentally disabled persons already served was subtracted from the estimated number in the region, leaving a final figure (expressed as a percentage) of the estimated number of disabled in the region needing services.

C. Weighting System

No established system of weighting factors in terms of relative importance made it necessary to place arbitrary values on the data categories. The population characteristics were given a base value of one. Such things as income, unemployment, substandard housing, etc. were more significant in estimating need; therefore, they were given a value of 1.5. Resources serving the developmentally disabled, being the most important factor related to need for new services, were given a weight value of 2.5 on the summary table.

D. Determination of Priority

The six regions were ranked on each of the three categories. They were ranked according to greatest need for each index, a rank of one indicating top priority. The ranks for each index within a category were then combined by simple addition (since each index in all categories. received equal weight). In the column at the extreme right, these sums were ranked, the lowest sum receiving a rank of one. A table was constructed for each of the three categories. A summary table was

prepared to record the ranks for the three categories. The final priority determination was reached by multiplying these ranks times the weight factor of each category, then adding the products and ranking the sums. The lowest value received a rank of one, indicating the area with the highest priority.

The tables showing the actual calculations are on the next several pages.

PRIORITY DETERMINATION AMONG REGIONS

POPULATION CHARACTERISTICS

Region	Population Density 1970 Population/ Square Miles			% Population Change	% Population Under 15			% Population in Rural Areas			Rank of Category	
	Numbers	Rate	Rank	Average%	Rank	Numbers	Rate	Rank	Rate	Rank	Sum of Ranks	Rank of Sums
1	$\frac{94,886}{14,110}$	6.7	2	-10.0	2	$\frac{26,212}{94,886}$	27.6	4	72.3	4	12	3
2	$\frac{96,984}{15,171}$	6.4	1	-3.3	3	$\frac{27,066}{96,984}$	27.9	3	84.9	1	8	1
3	$\frac{215,963}{14,966}$	14.4	4	2.1	5	$\frac{57,729}{215,963}$	26.7	5	79.9	3	17	5
4	$\frac{214,271}{21,033}$	10.2	3	-2.6	4	$\frac{61,890}{214,271}$	28.9	2	83.4	2	11	2
5	$\frac{359,065}{9,857}$	36.4	5	0.9	6	$\frac{90,924}{359,065}$	25.3	6	70.5	5	22	6
6	$\frac{502,554}{1,485}$	338.4	6	16.6	1	$\frac{156,579}{502,554}$	31.2	1	26.9	6	14	4

SOCIOECONOMIC CHARACTERISTICS

Table 1 of 2

REGION	PERCENT OF HOUSEHOLDS WITH CASH INCOME BELOW \$3,000		RATE OF UNEMPLOYMENT		RATE OF A.D.C. RECIPIENTS PER 1,000		
	Average %	Rank	Average %	Rank	Numbers	Rate	Rank
1	18.7	5	2.0	5	<u>2,193</u> 94,886	2.3	2
2	19.1	4	1.8	6	<u>1,375</u> 96,984	7.9	6
3	25.3	2	2.1	4	<u>2,439</u> 215,963	11.3	4
4	25.2	3	2.4	3	<u>1,926</u> 214,271	9.0	5
5	27.8	1	2.6	2	<u>4,197</u> 359,065	11.7	3
6	14.9	6	2.8	1	<u>17,290</u> 502,554	34.4	1

SOCIOECONOMIC CHARACTERISTICS

Table 2 of 2

REGION	INFANT MORTALITY RATE PER 1,000			UNITS LACKING ONE OR MORE PLUMBING FACILITIES		UNITS WITH MORE THAN 1.00 PERSONS PER ROOM		RANK OF CATEGORY	
	Numbers	Rate	Rank	Rate (%)	Rank	Rate (%)	Rank	Sum of Rank	Rank of Sum
1	$\frac{28}{1,348}$	20.8	1	4.5	5	7.0	2	20	3
2	$\frac{26}{1,418}$	18.3	3	5.4	4	6.1	4	27	6
3	$\frac{52}{3,324}$	15.6	4	6.1	3	5.5	5	22	5
4	$\frac{48}{3,358}$	14.3	6	8.1	1	6.8	3	21	4
5	$\frac{78}{5,376}$	14.5	5	7.0	2	4.1	6	19	2
6	$\frac{172}{9,624}$	18.5	2	3.3	6	7.2	1	17	1

SURVEY OF AREA NEEDS
DEVELOPMENTAL DISABILITY RESOURCES

A	B	C		D	E	F	G
Region	1970 Population	Estimated Developmentally Disabled Population in Need *		Number of Develop- mentally Disabled Being Served**	Number Not Being Served (Column C-D)	% Developmentally Disabled with Unmet Needs (Column E/C)	Rank
		MR	948				
		E.	474				
		C.P.	474				
1	94,818	Total	1,896	474	1,422	75%	2
		MR	971				
		E.	485				
		C.P.	485				
2	97,034	Total	1,941	742	1,199	62%	5
		MR	2,171				
		E.	1,085				
		C.P.	1,085				
3	217,044	Total	4,341	1,310	3,031	70%	3
		MR	2,144				
		E.	1,071				
		C.P.	1,071				
4	214,289	Total	4,286	1,040	3,246	76%	1
		MR	3,591				
		E.	1,795				
		C.P.	1,795				
5	359,065	Total	7,181	2,311	4,870	68%	4
		MR	5,013				
		E.	2,506				
		C.P.	2,506				
6	501,243	Total	10,025	5,126	4,899	49%	6
		MR	14,836				
		E.	7,417				
		C.P.	7,417				
Total	1,483,493	Total	29,670	11,003	18,667	63%	

*2% of Total Population

**Based on a Statewide Survey of Resources and Needs of the Mentally Retarded with Special Problems, June, 1971
available from the State Office of Mental Retardation.

SUMMARY TABLE
PRIORITY DETERMINATION AMONG REGIONS

REGION	POPULATION Weight = 10		SOCIO-ECONOMIC Weight = 15		DEVELOPMENTAL DISABILITY RESOURCES Weight = 25		SUM OF RXW	FINAL RANK
	Rank	RxW	Rank	RxW	Rank	RxW		
1	3	30	3	45	2	50	125	2
2	1	10	6	90	5	125	225	6
3	5	50	5	75	3	75	200	4
4	2	20	4	60	1	25	105	1
5	6	60	2	30	4	100	190	3
6	4	40	1	15	6	150	205	5

APPENDIX E

Procedures for Determination of Urban
and Rural Poverty Areas, State of Nebraska

ATTACHMENT 3.3

DETERMINATION OF URBAN AND RURAL POVERTY AREAS

Under the terms of this State plan, special financial and technical assistance shall be furnished to public and nonprofit private agencies and organizations engaged in providing services and facilities for persons with developmental disabilities who reside in urban and rural poverty areas. The Federal Share for the cost of planning, administration, and services for the fiscal year ending June 30, 1972, may be up to 90 per centum of the expenditures for projects located in such designated poverty areas.

A method of designating poverty areas in Nebraska on the basis of several factors was devised for the State Department of Health by Dr. Chris Gregg, Sociologist; in conjunction with Mr. William Hinze, Statistician for the Special Survey of Resources and Needs of the Mentally Retarded with Special Problems administered by the Office of Mental Retardation. Assistance in computer programming, analysis, and interpretation was provided by Dr. Wayne Gregg, Department of Sociology, University of Nebraska. The urban and rural poverty areas designated by this method are included in the Nebraska Hill-Burton State Plan.

The method of designating poverty areas in Nebraska included variables chosen with the following criteria in mind: (1) most reliable data available at this time and (2) data that has been established as being correlated with poverty. All data was reported on a county basis for the designation of poverty areas for the entire State. In addition, urban areas of Lincoln and Omaha are currently being analyzed as 1970 census data becomes available on a census tract basis. To summarize, poverty area designations for the State as a whole have been made by county for the 1972 State Plan.

The variables used in the designation of poverty areas on a county basis, taken from the advance reports of the 1970 census for Nebraska, are: Population 65 years of age and over, percent of families with female heads with children under 18 years of age, percent of occupied housing units lacking some of all kitchen facilities, percent of occupied housing units lacking some or all plumbing facilities, and percent of occupied housing units with more than one person per room. Additional variables were: infant mortality rates for 1969, percent of population receiving ADC payments for Fiscal Year 1969-1970, per capita income in 1968, percent of households with cash incomes below \$3,000 per year from the Sales Management Corporation Survey of 1970, and rates of unemployment in 1969.

Factor analysis showed six of the ten variables accounted for 84 percent of the variance. These six were: percent of occupied housing units lacking some or all plumbing facilities, percent of occupied housing units lacking some or all kitchen facilities, percent of population 65 and over, percent of occupied housing units with more than one person per room, rate of unemployment, and percent of families with female headed households with dependent children.

The variables were converted to standard scores using the formula: $\text{Raw score} - \text{mean} / \text{standard deviation}$. Standard scores allow for comparisons

between variables as well as among counties on the various factors used.

The standard scores on these six variables were added together; an average score was then found for each county. The counties were then ranked from highest to lowest, with the highest score indicating greatest poverty.

An arbitrary cutting point of the twentieth percentile of the counties was used to designate poverty areas. This was based on the

designation in the Federal regulations for the Hill-Burton Act of the twentieth percentile as the cutting point for poverty areas based on median family income and on a natural breaking point in the data itself.

An alphabetical list of the resulting 20 counties designated as poverty areas by the above method follows. A ranking of the counties with the average standard scores plus a map locating the counties are included. More complete statistical data is available from the State Agency.

The State Developmental Disabilities Planning and Advisory Council has determined that for 1972 funds, consideration can be given to applicant agencies for 90-10 matching if the applicant agencies can show to the satisfaction of the single State Agency that at least 51% of the clients to be served in the proposed project are from a poverty area.

Counties Ranked by the Following Six Variables:

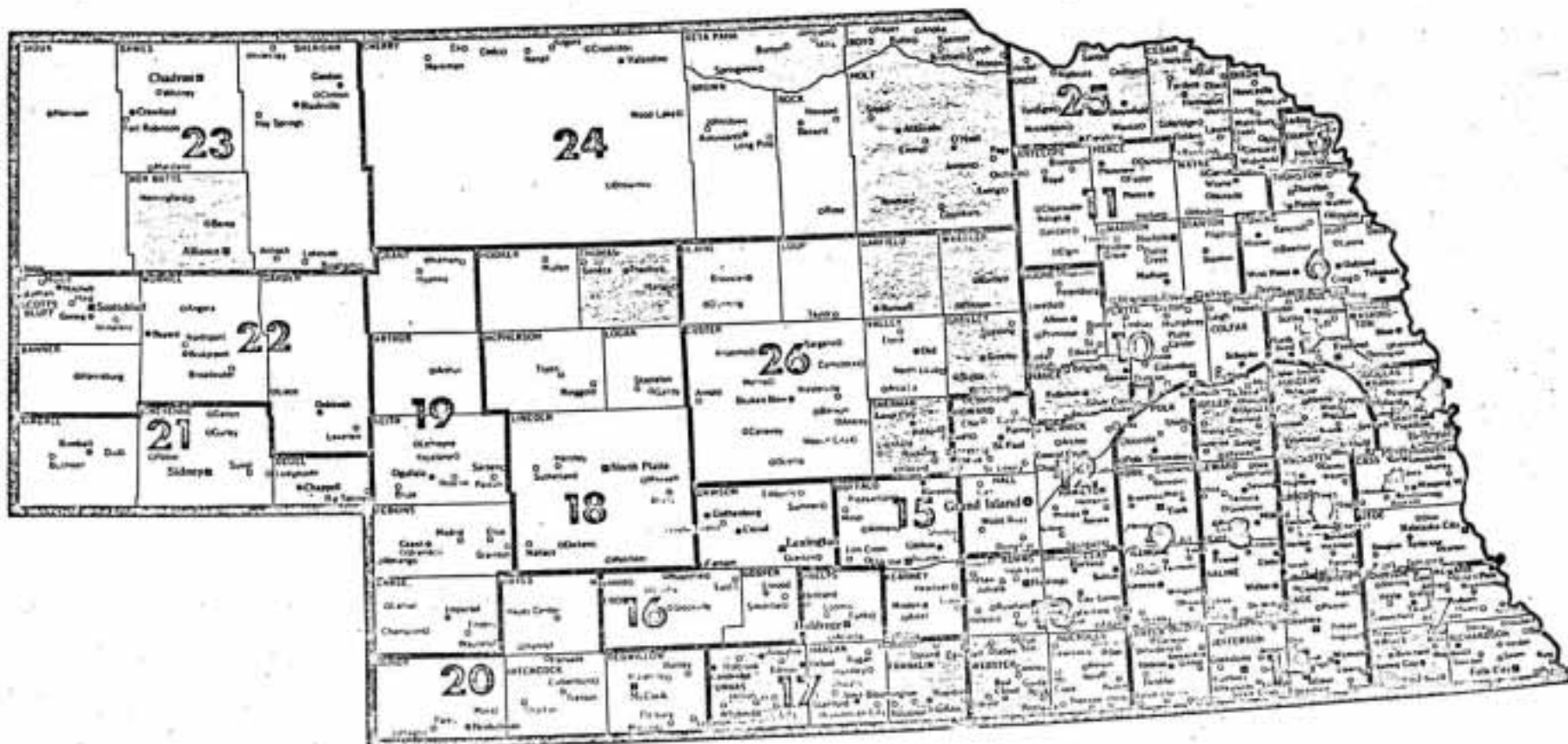
Percent of Population 65 and over, Percent of Occupied Housing Units Lacking Some or All Plumbing Facilities, Percent of Occupied Housing Units Lacking Some or All Kitchen Facilities, Percent of Housing Units with more than One Person Per Room, Rate of Unemployment, and Percent of Families with Female Heads with Dependent Children.

<u>County</u>	<u>Average Standard Score</u>
Thurston	3.495
Sherman	0.792
Pawnee	0.676
Garfield	0.606
Butler	0.592
Wheeler	0.550
Holt	0.485
Knox	0.479
Cedar	0.450
Dakota	0.368
Box Butte	0.354
Greeley	0.339
Webster	0.332
Keya Paha	0.320
Franklin	0.312
Nance	0.294
Boyd	0.291
Thomas	0.243
Saunders	0.228
Furnas	0.224

ALPHABETICAL LIST OF NEBRASKA COUNTIES DESIGNATED AS POVERTY AREAS

1. Box Butte County
2. Boyd County
3. Butler County
4. Cedar County
5. Dakota County
6. Franklin County
7. Furnas County
8. Garfield County
9. Greeley County
10. Holt County
11. Keya Paha County
12. Knox County
13. Nance County
14. Pawnee County
15. Saunders County
16. Sherman County
17. Thomas County
18. Thurston County
19. Webster County
20. Wheeler County

NEBRASKA POVERTY AREAS



APPENDIX F

Indicators and Weighting Schemes, State of Wisconsin,
Department of Health and Social Services, Division of
Mental Hygiene

CONSIDERATIONS IN THE DESIGN OF A PRIORITY SYSTEM

In the design of a priority system and the selection of indicators, a number of aspects of priority systems in general must be considered:

1. It is difficult to anticipate all the problems which may arise in adapting available data to the preconceived priority system. The intricacies and limitations of the data may result in alterations to the system at the time the indicators are calculated.

2. The value of a priority system is dependent on the data used to measure indicators. Indicators should be selected for which the data has the following characteristics:

a. High Comparability Throughout the State—Frequent discrepancies resulting from differences in attitudes, reporting skills, definitions and local bias, may affect the comparability of the data. b. Stability of Data—Utilization of data which is outdated and has changed drastically is to be avoided. Also, data based on events which occur rarely may result in the presence or absence of a single "case" significantly affecting the rank in a given area.

c. Range of Distribution—Some events occur at a fairly uniform rate throughout the state. In general, if for a particular indicator there is little difference between the highest and lowest ranking area in the state, it should not be considered. An indicator which discriminates well between a few areas but poorly among a majority also has questionable usefulness. This would occur in terms of an

indicator reflecting percent of non-white population since the major populations of non-whites in Wisconsin are concentrated in a few areas of the state.

3. Weighing is an important consideration in designing a priority system.

Straight summing across the ranks of several indicators for a given area amounts to assigning a weight of one to each indicator, and in effect, to a statement that each indicator is considered of equal importance with every other one. When such a simple summation of ranks is used, the greater the number of indicators, the less important each becomes in the final determination of rank.

4. The Council has authority to assign increased weight to indicators which reflect the program emphasis for the fiscal year and less emphasis to those indicators considered to be of less importance. In assigning weights, not only the reliability of the data and the Council determined priorities must be considered, but also the fact that all indicators may not be mutually exclusive. In some cases, indicators which are designed to measure a different factor may, in effect, be measuring similar factors or a third factor. In such cases, it may be advantageous to give less weight to each of the two indicators.

October 1, 1971

PRIORITY SYSTEM FOR APPROVAL OF COMMUNITY PROJECTS

ISSUE To select indicators to be used to determine priority of community projects for Developmental Disabilities funding. This issue needs to be resolved at this time to include in the applications distributed to communities, a summary of the general factors which will determine priority of projects.

ISSUE DEFINITION The Regulations and Guidelines provide the following summarized information in regard to determining priorities for approval of community projects:

- A. Priority for approval of construction projects is based on one major factor.
 - 1. Relative Need of the Geographical Area.*
- B. Priority for approval of services and planning projects is based on two combined factors.
 - 1. Relative Need of the Geographical Area.*
 - 2. Rating of the Proposed Project.

Therefore construction projects which are approved by the Social and Rehabilitation Service are submitted to the Regional Office solely on the basis of the relative need of the area from which the project originated. Services and planning projects, which are approved on the state level are approved on the basis of the relative need of the area from which they originated and on the rating of the proposed projects.

The Council's role in determining priorities relates to the selection and weighing of indicators to measure the two factors of relative need and the rating of the proposed projects.

Indicators suggested by the Regulations, Guidelines and staff members have been examined. An attached paper, "Indicators Excluded from Consideration in the Priority System," summarizes the reasons for rejection of several of the suggested indicators. The remaining suggested indicators are presented in this paper for Council consideration. These indicators are categorized into three groups:

- 1. Indicators of Relative Need—to be used to determine the priority for construction projects
 - a. Percent of Need Met by Type of Service
 - b. Percent of Need Met by Age Group
 - c. Poverty Ratio
 - d. Other Area Characteristics
 - 1) Combined Infant and Fetal Mortality Rate
 - 2) Percent of Unemployed
 - 3) Density per Square. Mile
- 2. Indicators for Rating of Proposed Service Projects—to be combined with Indicators of Relative Need to determine the priority of service projects
 - a. Resources of Other Funding Programs to Provide Services
 - b. Capacity of Project to Fill High Unmet Need by Type of Service

- c. Realism of Budget and Means and Methods
- d. Evaluation

3. Indicators for Rating of Planning Projects—to be combined with Indicators of Relative Need to determine priority of planning projects.

- a. Realism of Budget and Means and Methods
- b. Adequacy of Proposed Planning Process

The above conceptualization of a priority system and the indicators suggested are not to be perceived as inflexible staff recommendations. Rather, the complexity of the issue of priorities necessitates that examples be used to illustrate some of the issues and to stimulate discussion. The Council will be requested to delete, add or make alterations in the system and to make key decisions on the weighing of various indicators. To assist in this process Priority Issues are denoted to emphasize key decision points. In the interest of brevity, only the primary considerations are presented in this paper. Additional supportive documents are available from the staff.

INDICATORS OF RELATIVE NEED OF THE AREA

INDICATOR	DESCRIPTION	CONSIDERATION
<p><u>Percent of Need Met by Type of Service</u></p>	<p>For each of the sixteen elements of service the percentage of the need met by existing services is calculated by comparing the number of developmentally disabled persons known to be receiving each type of service on an average caseload basis to the estimated number needing each type of service. The number of persons known to be receiving a service is determined from an inventory of programs of the specified Federal-State agencies and other programs serving the developmentally disabled and includes persons from the county served both within the county and in programs outside the county. The estimated number needing a particular service is calculated from a variety of sources including: Federal guidelines, agency proposals, waiting lists, planning documents, etc.</p> <p>For each type of service, the county with the lowest percentage of need met is ranked number seventy-two and the highest percent of need met is number one.</p> <p>For several of the sixteen elements of service as defined by the Regulations it may be impossible to calculate reliable percentages of need met. For some elements of service, such as transportation, it may be impossible to estimate an accurate need for service. For other elements of service, such as protective, and other social and socio-legal services, the number of individuals receiving this service is so insignificant, statistical measure of unmet need is unwarranted. In terms of these exceptions, it may be necessary to assume a uniform need throughout the state.</p>	<p>This indicator provides a means of measuring the relative extent of need by type of service.</p> <p>The assumption is made in this indicator that, over all service areas, need estimates for each type of service remain constant. Although this assumption has limited value, it is the best and only assumption that can be made from available data at this time. It must also be understood that need estimates do not take into account the adequacy of existing programs or of the facilities in which they are housed.</p> <p>Utilization of county of residence of persons to determine the number of persons receiving service both within and outside the county, may not truly reflect, in some cases, the need for community program development. It is particularly disadvantageous to those counties, who, through lack of local programs, have had to utilize residential facilities outside the county for care of the more severely developmentally disabled.</p> <p>Rather than merely summing across the rank of each service to yield a single rank reflecting total need for services, priority could be assigned to a particular type or types of services by giving increased weight to the ranks of the counties for that service. This indicator has an advantage in providing a means to combine priority by type of service with data on extent of need. It thereby minimizes the error which might occur if the Council were to merely designate a particular service as high priority, say Information and Referral, when the data indicates the most pressing need of the area is for training services.</p> <p><u>Priority Issues</u>--Should a particular type or types of service be given increased weight?</p>

INDICATORS OF RELATIVE NEED OF THE AREA

INDICATOR	DESCRIPTION	CONSIDERATION
<u>Percent of Need Met by Age Group</u>	<p>For each of the age groups delineated in the Plan (0-5, 6-20, 21+), the percentage of the population served by existing services is calculated by comparing the number of developmentally disabled persons known to be receiving services to the total population of that age group. The number of persons known to be receiving services is determined from an inventory of programs in the specified Federal-state agencies and other programs serving the developmentally disabled and includes persons from the county served both within the county and in programs outside the county.</p> <p>For each age groups, the county with the lowest percentage of the age group served is ranked seventy-two and the highest percent of the age group served is ranked one.</p>	<p>This indicator provides a means of measuring, to some degree, the extent of need by age groups.</p> <p>The reliability of this indicator, however, is somewhat limited in that the number of persons served by age group should be compared to the prevalence of developmental disabilities in that age group. Unfortunately, although prevalence by age is available for mental retardation, it is impossible to determine prevalence by age for the other disabilities at this time. Comparison of the number of persons served to the total population does provide, however, a means of comparing the relative need for service by age group among the counties.</p> <p>Utilization of county of residence of persons to determine the number of persons receiving service both within and outside the county may not truly reflect, in some cases, the need for community program development. It is particularly disadvantageous to those counties who, through lack of community program have had to utilize facilities outside the county for care of the developmentally disabled.</p> <p>Rather than merely summing across the rank of each area to yield a single rank of percent of the total population served, the Council may assign priority to a particular age group by giving increased weight to the ranks of the areas for that age group. This indicator has an advantage in providing a means to combine priorities by age group with actual extent of need. It, thereby, minimizes the error which might occur if the Council were to merely designate a particular age group as top priority, say adults, when the data on percent served indicate the most pressing need of the area is for services for children.</p> <p><u>Priority Issue</u>--Should a particular age group be designated as a high priority and given increased weight?</p>

INDICATORS OF RELATIVE NEED OF THE AREA

INDICATOR	DESCRIPTION	CONSIDERATION
3. Poverty Ratio	<p>This indicator represents the ratio of the number of poor families to the total number of families in the service area. A poor family is defined by the Office of Economic Opportunity as a family which receives an income below the Social Security Administration poverty cutoff. The poverty line varies with the size of the family and place of residence, whether it is rural or urban.</p> <p>The most recent poverty data, that obtained from the 1966 County Profiles prepared by the Office of Economic Opportunity, will be used.</p> <p>The county with the highest percentage of families below the poverty level is ranked number seventy-two and the county with the lowest percentage is ranked number one.</p>	<p>The capacity to provide services and facilities is generally assumed to be related to the ratio of poor families within a service area. There is also considerable evidence of a higher incidence of developmental disabilities among low income families. These low income families are often unable to afford the prenatal and maternal care, nutritional diet and other preventive measures.</p> <p>The Regulations clearly specify that financial assistance is to be given to designated poverty areas and also that poverty areas are to be an indicator in the priority systems. It is not clear, however, whether only designated poverty areas are to be given consideration in the development of priorities or whether the poverty level of all counties is to be considered. This indicator gives consideration to the poverty level of all areas, not only those designated poverty areas. Since designated poverty areas are already given special consideration through increased funding, this method of incorporating the poverty indicator into the priority system provides a more precise means of discriminating among the various poverty levels of all counties in the state.</p>
4. <u>Other Area Characteristics</u> *		<p>* Since these indicators are included to describe the general characteristics of an area, they may have less direct correlation with the priorities determined by the Council. The Council, therefore, may wish to assign a relatively lower weight to these factors.</p>
a. Combined Infant and Fetal Mortality Rate	<p>The combined infant and fetal mortality rate represents the number of deaths under one year of age, including the neonatal and fetal deaths, per 1,000 deliveries (live births plus fetal deaths) for a five year period by county. The county with the highest rate of infant and fetal mortality is ranked number seventy-two and the county with the lowest rate is ranked one.</p>	<p>This indicator reflects to some extent the level of health services and "the way of life" in the service area. The combined infant and fetal mortality rate may also be correlated with the lack of maternal and prenatal health care which is correlated with the prevalence of developmental disabilities.</p>

INDICATORS OF THE RELATIVE NEED OF THE AREA

INDICATOR	DESCRIPTION	CONSIDERATION
b. Percent of Unemployed	<p>This indicator is the percent of unemployed adults compared to the total work force as reported by the State Employment Department.</p> <p>The county with the highest percent of unemployment is ranked number seventy-two, and the lowest percent of unemployment is ranked one.</p>	<p>In addition to being an indicator of the general economic status of a county, level of unemployment may also reflect the capacity of a county to "absorb" the developmentally disabled. An area with high unemployment, particularly in industry, is less likely to be able to provide employment for adult developmentally disabled.</p>
c. Density per Square Mile	<p>This indicator represents the total 1970 population of a county divided by the total square miles in the county. Ranking is determined from the median value. The counties with population densities per square mile farthest from the median either high or low, are assigned rank seventy-two, and so on.</p>	<p>This method gives first priority to both extremes of high and low population density where the need is the greatest. High density areas are thought to be good indicators of need because of the positive correlation with developmental disabilities. In some cases, however, low density is coupled with an absence of resources and may imply the need for development of additional services for the area.</p>

INDICATORS FOR RATING OF PROPOSED SERVICE PROJECTS*

INDICATOR	DESCRIPTION	CONSIDERATIONS
<u>Resources Of Other Funding Programs to Provide Services</u>	For this indicator, projects would be rated on a simplified "all or nothing" scale. If the committee determines that the proposed project would be eligible for funding under other Federal or State programs such as Title I, Purchase of Services, State Day Care reimbursement, etc., no points would be given to the project. If the committee determines the proposed project to be a new service, not eligible for funding under these programs, it would be given the total points or total weight assigned to this indicator.	<p>The Regulations specify that the extent of the resources of other funding programs to provide the proposed service is to be considered. It is also clearly specified that Developmental Disabilities funds are to be used to complement and augment, rather than duplicate or replace, services or funds provided from other sources. This indicator provides a method for giving low priority to or excluding projects for services that could be eligible for funding under other programs.</p> <p>This might also provide a method of giving increased priority to innovative programs or those which provide for a new type of modality or means of providing service, models of service, or delivery systems. This is based on the assumption that innovative type projects would probably not be eligible under other funding programs and would therefore be given a higher priority under this indicator.</p> <p>The nature of this indicator suggests that rather than being considered as one of many indicators determining the priority of a project, it might be considered the primary indicator. Should the Council consider eligibility under other sources to be of utmost significance, this indicator might be the primary or first indicator on which to assess projects. If the project could be eligible under other sources, it would be immediately rejected for consideration and not rated on the other indicators.</p> <p><u>Priority Issue</u>--Should eligibility of a proposed service for other funding sources exclude it from consideration from Developmental Disabilities funding, or should it merely give the project lower priority?</p>

* For these indicators, submitted projects would be rated on a simplified point scale by a designated committee. The priority for service projects would be the combined rank from the Indicators of Relative Need of the Area and these Indicators for Rating of Proposed Service Projects.

INDICATORS OF RATING OF PROPOSED SERVICE PROJECTS

INDICATOR	DESCRIPTION	CONSIDERATIONS
<p><u>Capacity of Project to Fill High Unmet Need By Service</u></p>	<p>In rating of the indicator, the extent of need met in each county for each type of service would be ranked from low to high extent of need met. Extent of need met is determined by comparing the number of developmentally disabled known to be receiving services to the estimated number needing each type of service.</p> <p>An example of the rating scale would be to give four points (or multiples of four depending on the weight assigned the indicator) to a proposed project for a service which is one of the top four most needed services in a county. If the proposed service is ranked five through eight in terms of extent of need met, three points (or multiples of three, depending on the weight assigned to the indicator) would be given, and so forth. If the proposed service is one which the Council has given an overall priority to, additional points would be incorporated in the rating scale. If the proposed project is to provide more than one service, the points assigned to each service on the basis of unmet need plus additional points for high priority service, would be divided by the number of services to be provided. This would yield a single rating for the project. The above example, of course, is open to a number of variations.</p>	<p>This indicator would measure the "fitness" between the service proposed by the project and the need in the area. The effectiveness of the proposed project in filling documented service gaps and duplicating existing services can be assessed. It could also provide additional points to those projects intending to provide services designated by the council as high priority.</p>
<p>1. <u>Realism of Budget and Means and Methods</u></p>	<p>The means and methods of accomplishing the project and the project budget would each be rated on a point scale on the basis of the following criteria: excellent, realistic, not very realistic, unrealistic. The points assigned to each criterion on the scale would be determined by the weight given to this indicator by the Council.</p>	<p>This indicator provides a way of assessing the capacity of an applicant to carry out the project and of assessing whether the budget and the means and methods are realistic in terms of accomplishing the specific results expected to be achieved. This indicator is important in ensuring that funds are not allocated to a project, which, although highly desirable, would be impossible to complete effectively.</p>

INDICATORS OF RATING OF PROPOSED SERVICE PROJECTS

INDICATORS	DESCRIPTION	CONSIDERATIONS
01-3 Evaluation	<p>To determine the adequacy of the evaluation process in the proposed application involves review of both project objectives and evaluation methodology. Each submitted application will be rated on a point scale by the designated committee with assistance from the Developmental Disabilities Evaluation Consultant.</p> <p>The criteria for rating the evaluation methodology and objectives are as follows:</p> <ol style="list-style-type: none">1. Degree to which objectives are end-oriented2. Degree to which objectives specify definite recipients3. Whether nominal definitions are provided for all desired ends4. Whether operational objectives are provided for all desired ends5. The effectiveness of the process methodology described. <p>The priorities assigned to each criterion in the scale will be determined by the weight assigned to this indicator by the Council.</p>	<p>On the basis of the rating scale for this indicator, the means and methods of certain projects might be rated as unrealistic. In such cases, it would be possible to reject such applications for consideration. This would give the indicator primary importance. It should be emphasized that the Council retains the prerogative to allocate funds at a higher or lower level than the budget proposal contingent upon the applicant's agreement to revise the objectives and to carry out the means and methods as recommended by the Council.</p> <p><u>Priority Issue</u>--If the budget and means and methods in a proposed project are unrealistic, should the project be rejected or merely given lower priority?</p> <p>The Developmental Disabilities Act places great emphasis on evaluation. The allocation of Federal funds to a specific project requires information as to the performance and results of that project. Without an adequate evaluation process, the Council has no way of determining if the project justified the priority and the money allocated to it. Further adequate feedback allows the Council to determine if the specific project should be funded or encouraged in the future for different geographical areas or for different age or disability groups.</p> <p>It should be recognized that small, less sophisticated programs will not have as great an expertise in evaluation methodology as the larger programs. The suggested criteria for this scale attempt to take into account this indicator.</p>

INDICATORS FOR RATING OF PROPOSED PLANNING PROJECTS*

INDICATOR	DESCRIPTION	CONSIDERATIONS
<u>Realism of Budget and Means and Methods</u>	<p>The means and methods of accomplishing the project and the project budget would each be rated on a point scale on the basis of the following criteria: excellent, realistic, not very realistic, unrealistic. The points assigned to each criteria on the scale would be determined by the weight given to this indicator by the Council.</p>	<p>This indicator provided a way of assessing the capacity of an applicant to carry out the project and of assessing whether the budget and the means and methods are realistic in terms of accomplishing the specific results expected to be achieved. This indicator is important in ensuring that funds are not allocated to a project, which, although highly desirable, would be impossible to complete effectively.</p> <p>On the basis of the rating scale for this indicator, the means and methods of certain projects might be rated as unrealistic. In such cases, it would be possible to reject such applications for consideration. This would give the factor primary importance. It should be emphasized that the Council retains the prerogative to allocate funds at a higher or lower level than the budget proposed contingent upon the applicant's agreement to revise the objectives and to carry out the means and methods as recommended by the Council.</p> <p><u>Priority Issue</u> -- If the budget and means and methods in a proposed project are unrealistic, should the project be rejected or merely given lower priority?</p>
<u>Adequacy of Proposed Planning Process</u>	<p>All submitted applications for planning projects would be ranked on a simplified scale on the basis of the process to be employed in carrying out the project. The criteria on which the scale is based are as follows:</p> <ol style="list-style-type: none"> 1. Degree to which the process is based on an actual assessment of need. 2. Degree to which other planning groups and agencies are involved in the process. 3. Degree to which actual consumers of services are involved. <p>The points assigned to each criterion in the scale will be dependent on the weight assigned to this indicator by the Council</p>	<p>The nebulous nature of many planning projects requires that there be an assurance that the process involved justifies the allocation of funds. A planning project which duplicates existing planning efforts or which does not involve the groups and agencies to be affected by the Plan does not justify the use of Developmental Disabilities funds.</p>

*For these indicators, submitted projects would be rated on a simplified point scale by a designated committee. The priority for each planning project would be the combined rank from the Indicators of Relative Need of the Area and the Indicators for Rating of Proposed Planning Project.

APPENDIX G

Recommendations from the Wisconsin Department of Health and Social Services, Division of Mental Hygiene, for the estimation of the prevalence of developmental disabilities.

DEVELOPMENTAL DISABILITIES PREVALENCE ESTIMATES

Prevalence estimates are an integral part of the planning process. Unless the approximate number of individuals requiring service is known, it is not realistically possible to ascertain needs for service. It is essential then that care be taken in arriving at estimates having the greatest likelihood of reflecting the true prevalence. However, this task is complicated by the present lack of true epidemiological studies for developmental disabilities. Therefore, any projection of the number of developmentally disabled persons in need of services must always be considered an estimate, and as such, be interpreted with caution.

For purposes of this discussion, developmental disability means a disability attributable to mental retardation, cerebral palsy, epilepsy, or another neurological condition of an individual closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals. Further, the disability originates before the person attains age eighteen, has continued or can be expected to continue indefinitely, and constitutes a substantial handicap to the individual. With respect to actual numbers, consideration must be given to the meaning of "substantial continuing handicap."

Elizabeth Boggs, in "Summary of Recommended Estimates on. Extent of Developmental Disability," 1971, suggested that the concept of developmental disability does not imply a static condition or a stalling of development. Classifying an individual as developmentally disabled does not imply that a child so designated is destined to be a substantially disabled adult. However, uncomplicated mild mental retardation leading to competitive employment is not a "substantial continuing handicap," seizures which are controlled do not constitute a "substantial continuing handicap," and the intelligent cerebral palsied person with a slight tremor is not substantially handicapped.

It is therefore recommended that in estimating the extent of developmental disabilities, emphasis should be placed on the common functional needs and the extent of overlapping multiple handicaps rather than on distinct diagnostic categories.

Although prevalence estimates have been determined for specific disabilities such as mental retardation and epilepsy, the emphasis has been on distinct diagnostic categories rather than the approach advocated here, and as such, were considered unsuitable for estimating prevalence for the developmental disabilities. For example, many authorities agree that about three per cent of the total population will demonstrate difficulties in environmental adjustment associated with subnormal intelligence in sufficient degree to result in their being identified as retarded at some point during their lives. Erroneously, this morbidity figure is often confused with prevalence of mental retardation. Prevalence refers to the number of persons who will be identified as retarded at any given point in time rather than at some point during their lives. Further, this three per cent estimate includes those who fall into borderline category, the majority of whom would not be substantially handicapped. Since the intent of the Developmental Disabilities Act is to provide services to those with substantial continuing handicaps, it would be inappropriate to initiate planning activities based on this widely accepted three per cent estimate,

A method emphasizing the common functional needs and the extent of overlapping multiple handicaps rather than distinct diagnostic categories was also demonstrated by Elizabeth Boggs.

She estimated that the triad (mental retardation, cerebral palsy and epilepsy) accounts for 75 per cent of all severe adult disability originating in childhood. If childhood schizophrenia and all "other neurological disorders" are added, then at least 85 per cent of all childhood disability is accounted for.

The analysis by Elizabeth Boggs of the categories of disabilities within the developmental disability is shown below in Table A.

TABLE A *

PERCENT OF ALL DEVELOPMENTAL DISABILITIES

	Mental Retardation (alone)	49.5 %	} 73.5 % Mental Retardation
	Other Conditions implying MR	3.7	
14 %	Cerebral Palsy with MR	10.0	
	Epilepsy with MR	10.3	
13 %	Cerebral Palsy (alone)	3.6	} 80 % Nonduplicated MR, Cerebral Palsy and Epilepsy
	Epilepsy (alone)	2.5	
		<u>79.6 %</u>	
	The 20 per cent remaining includes (All Developmental Disabilities):		
	Childhood schizophrenia	6.2 %	
	All Other Mental	1.9	
	All Other Nervous System and Sensory	3.6	
		<u>11.7 %</u>	
	Physical disorders (muscular, etc.)	8.7 %	

These percentages are applied to the prevalence estimates derived in "Phase I - 1970 Projections of the Mentally Retarded in Wisconsin" developed by Mr. Kary W. Hyre, Bureau of Planning Evaluation Research, Division of Mental Hygiene, and based on extensive work by the California Study Commission on Mental Retardation.

The California study yielded a total prevalence rate of 1.83 per cent for 1960. When the distribution of rates was applied to Wisconsin, the changes in the age distribution of Wisconsin's population from 1960 to 1970 raised the overall rate to 1.857 per cent. The major purpose of the Wisconsin study was to develop a statewide prevalence projection of Wisconsin's mentally retarded population and to delineate the projections by age group, level of retardation and age by level simultaneously. Therefore, the 1.857 percent represents a pragmatic service oriented goal which will require a great deal of effort to *Boggs, Elizabeth. "Summary of Recommended Estimates on Existence of Developmental Disability", 1971

meet. Further, since both the California study and the Wisconsin study upon which it was based, exclude borderline retardation, the 1.857 percent figure is more representative of the substantially handicapped population of mentally retarded persons and is thus in conformance with the intent of the Developmental Disabilities legislation.

The 1.857 percent figure was based on 1970 census projections since actual 1970 information was not available at the time of the study. By incorporating the methods used and applying them to 1970 census data a new prevalence estimate of 1.900 percent was generated.

This estimates that there are approximately 83,900 mentally retarded individuals (excluding those classified as borderline) in Wisconsin's 1970 population of 14,417,731. By incorporating the prevalence estimate for mental retardation with the percentage distribution estimates for the other developmental disabilities, the following estimated prevalence rates are obtained. Within the total developmental disabilities population in Wisconsin, 83,900 or 73.5 percent are mentally retarded, either alone or in combination with other disabilities. Therefore, by means of a simple equation, it is now possible to determine a prevalence estimate for the developmental disabilities. In other words, if 83,900 is 73.5 percent of all developmental disabilities, then 114,170 is 100 percent of all developmental disabilities.

Returning to Table A, the following estimates are obtained:

Mental Retardation (alone)	49.5%	=	56,520
Other Conditions Implying MR	3.7%	=	4,220
Cerebral Palsy with MR	10.0%	=	11,420
Epilepsy with MR	10.3%	=	11,760
Cerebral Palsy (alone)	3.6%	=	4,110
Epilepsy (alone)	2.5%	=	<u>2,850</u>
Total (Triad)	79.6%		90,880
Childhood Schizophrenia	6.2%	=	7,080
All Other Mental	1.9%	=	2,170
All Other Nervous system and Sensory	3.6%	=	4,110
Physical Disorders (muscular, etc.)	8.7%	=	<u>9,930</u>
Total Mental and Physical	20.4%	=	23,290
<hr/>			
TOTAL (All Developmental Disabilities)	100.0%	-	114,170

114,170 = 2.584% of the total Wisconsin 1970 population.

APPENDIX H

Excerpts from the Developmental Disabilities State Plan - 1972,
Kansas State Board of Social Welfare

APPENDIX H

KANSAS PLANS FOR FISCAL YEAR 1972

Goals and Objectives

With the principle of continuous planning for the development of coordinated services in order to provide a comprehensive system of service delivery, the Council has adopted the following goals and objectives which are not listed in a priority arrangement:

1. To strengthen the existing community services specializing in caring for the developmentally disabled, such as day care centers and adult rehabilitation facilities serving the substantially handicapped.
2. To enable community facilities to expand their services in order that they may be more effective. This may be done by adding new staff, serving additional handicaps, etc.
3. To establish regional developmental disability planning councils in order to establish more broad based communications of developmental disabilities needs as well as to be in a position to more effectively plan for developmental disabilities services within the specified geographic areas.
4. To make certain that existing generic services through health, welfare, mental health rehabilitation and education would become more available to the substantially handicapped in the community.
5. To hire sufficient staff to effect ongoing planning throughout the state both with regional developmental disabilities councils as well as the State Council thereby insuring a coordinated planning program with other state agency planning divisions.
6. To encourage the provision of statewide services. In this manner various projects that would have statewide effect would be funded in order to better communicate the needs of the developmentally disabled, survey these needs, review existing programs and upgrade existing programs.
7. To provide in-service training and consultation to the community staffs both professional and para professional.
8. To plan for the establishment of community residential facilities that would care for the more substantially handicapped. Special residential facilities will be examined as well as new ones planned for construction.
9. Exploration will be made toward the establishment of a more uniform system in order to more realistically determine what services are currently being provided by what state and private agencies and to whom.

Breakdown of Proposed Expenditures

Of the \$210,842 projected for usage for Fiscal Year 1972, the following categorical breakdowns have been established: 1) Planning - -0-; 2) Administration - \$20,000; 3) Services - \$160,842; 4) Construction - \$30,000. In the category of services, the following agencies have been recommended to receive funds for a variety of intervention activities for the establishment and delivery of services: 1) The Kansas Association for Retarded Children has asked for funding of two individuals, one to help organize additional community services and ARC units throughout the state and the other to be a specialist in the development and initiation of recreational services. These individuals will be funded one half from Fiscal Year 1972 funds and one half from Fiscal Year 1973 projected funds.

2) The Kansas United Cerebral Palsy Association will be using \$30,000 to purchase day services from a variety of facilities for both children and adults not eligible to be funded by existing state or local agencies.

3) The United Agency for the Developmentally Disabled has asked for a staff person to assist in the provision and stimulation of expanded religious nature programs on an ecumenical basis throughout the state. This individual will also help to stimulate intervention of the church into more active participation in the problems faced by the developmentally disabled and their families. One half of this request will be funded in Fiscal Year 1972 and one half in Fiscal Year 1973.

4) Educational Care, Inc. is proposing to establish a regional boarding facility for trainable students attending a cooperative special education program. This organization will provide this special living arrangement on a four night a week basis throughout the school year.

5) The Division of Institutional Management is proposing to set up technical assistance through the provision of an in-service training program for the staff and board members of adult rehabilitation facilities serving the developmentally disabled.

6) The University of Kansas Medical Center has proposed to establish a metabolic survey service for the existing state institutions serving the mentally retarded as well as for direct referrals from the community. This service will be continued under their Fiscal Year 1973 budget.

The remaining service funds will go toward the improvement and expansion of adult residential and training services within private community facilities. These funds will be developed on a project basis and will be only for this fiscal year.

At this time there are no plans made for the expenditure of this money for planning or interstate. However, there is a proposed expenditure of \$30,000 for construction of two dormitories on a recreational site sponsored by the Kansas Jaycees United Cerebral Palsy. These dormitories will service several hundred children and adults throughout the state and will allow for use of this existing recreational facility several months of the year.